

**Communication Styles in Children and Young
People with Profound Mental Handicap:**

A Developmental Perspective

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I declare that this thesis is entirely my own work

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**I dedicate my thesis with affection and respect
to the children, young people and caregivers
who participated in the research**

ABSTRACT

Children with profound mental handicap pose particularly difficult challenges for parents, teachers and therapists because of their extremely low level of measurable achievement in all areas of their development. They have no formal system of communication and will remain at a pre-symbolic level of development throughout life. The absence of this developmental milestone is perhaps the most devastating feature of their handicap. Nevertheless, people with profound mental handicap do communicate with others and appear able to form emotional relationships, but little is understood of the underlying processes which make this possible. The aim of this study was to examine and describe the nature and content of communication in profound mental handicap.

The developmental level of people with profound mental handicap and their limited behavioural repertoire suggests that the normal development of emotional and social communication in infancy offers an appropriate model for the processes underlying their communication. By revealing what is shared in the two populations insight might also be gained into the robust elements of normal communication, i.e. those elements operating in both populations.

The investigation was divided into two studies. In Study 1 interactions between 12 children (aged 8-18 years) with profound mental and multiple handicaps and their caregivers (mothers and nurses) were described. Study 2 compared the communicative involvement of six young people with profound mental handicap (aged 14-26 years) when with three groups of adults who were differentiated by their personal knowledge of the young person and their previous experience in the field of profound mental handicap.

The two studies revealed that, beneath the apparent chaos and disorder, an ordered system of emotional communication is operating in children and young people with profound mental handicap, in common with similar observations in normal early development. The implications of these findings for the development of personal communication and relationships in children and young people with profound handicaps and the contribution of this knowledge to the understanding of the normal development of early communication are discussed. Possible therapeutic applications are also considered, proposing that close attention should be paid to the fundamental aspects of human behaviour which are shared in the general and profoundly mentally handicapped populations, influencing the practices which help children with profound mental handicap to move forward and out into the community of other human beings.

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CHAPTER 1: INTRODUCTION

Nonverbal communication is an effective medium for expressing and conveying emotional communication (Buck, 1984). Through their interactions with others, people are able to express and share their feelings and to form personal relationships. The experiences people have during their interactions can have a major effect on their inner lives, deeply affecting how they feel about themselves (Condon, 1980). Emotional communication forms a large part of human communication (Buck, 1984) and everyone has a basic need and right to enjoy this fundamental form of human contact in a way that is suited to his or her capacities.

Researchers continue to debate the extent to which non-verbal behaviour is innate or learned from the culture in which the individual lives. Cross-cultural studies suggest that some patterns of behaviour occur universally, appearing in the same social context and being similarly interpreted by the participants (Eibl-Eibesfeldt, 1972). Many researchers believe that innate and cultural factors both play a part and that humans learn how to use a system of communication that has deep biological roots (Buck, 1982).

1.1 Non-Verbal Communication

Non-verbal behaviour plays a part in all human interaction (Mayo and Henley, 1981), accompanying, modifying and complementing what a person is saying. It conveys information, intentionally or otherwise, about a person's moods and feelings through gestures, postures, facial expressions, eye contact, the ways in which he or she touches another or reacts to being touched, and his or her body movements.

Leudar's (1981) observations of a group of people with Down's syndrome showed that their body movements and postures reflected their social relationship with their conversation partner. He observed them during interactions with a stranger and with someone they knew and found that they moved less and in a more restricted way with a stranger. They also kept a greater distance and held an orientation that was either neutral, or

one that was turned away from the other person, and often adopted a closed posture.

1.1.1 Disruptions in Non-Verbal Communication

When a non-verbal behaviour occurs unexpectedly or in the wrong place, e.g. the behaviour occurs too early or too late, or an expected behaviour is absent, the effect on the communication can be very disruptive (Mayo and Henley, 1981). For example, Fraiberg (1974) describes how blind two- and three-month-old babies can mislead parents into thinking that they are not attending because the babies incline their heads in order to improve listening instead of seeking eye contact. She also noted that she did not talk to the blind babies in her studies as she did to the sighted babies. Fraiberg suggests that the reason for her reaction, and for the parents' misinterpretation, is because blind babies do not give the rewarding responses of smiling and facial focusing that sighted babies do. Smiling and eye contact are powerful incentives for caregivers (Emde, 1984) and their absence can cause a disincentive to communicate on the part of the caregiver. However, eye contact, though usual, is not an essential part of communication. Parents do develop good communication with children who are blind and with sighted children who avoid looking at other people.

Non-Verbal Communication in Children with Profound Mental Handicap

Children with profound mental handicap rely on non-verbal forms of communication for all their interpersonal contact. The developmental level of children with profound mental handicap places them in Piaget's sensorimotor stage, and although individual levels of attainment within this stage vary, the communication of all children is at a pre-symbolic level of development. The absence of this major developmental milestone is perhaps one of the most devastating features of their mental handicap.

The children do not have the full range of body movements, eye contact and facial expressions which are a usual and important part of interpersonal communication and their caregivers often have to work in the dark trying to unscramble and make sense of the child's behaviour. Physical disabilities can severely limit a child's range and control of movements, facial

expressions can be distorted and misleading and sometimes the actions the child uses may be obscured by unintentional movements. Difficulties in engaging the child's interest and maintaining his or her involvement affect all aspects of the child's life. The children pose particularly difficult challenges for parents, teachers and therapists because of their extremely low level of measurable achievements in all areas of development.

1.2 The Nature of Profound Mental Handicap

Profound mental handicap does not describe one 'condition' alone. Known causes include birth injury, chromosomal abnormalities and metabolic disorders and postnatal viral infections. However, the pathological cause of their profound mental handicap is possibly as many as fifty percent of children is unknown (Berg, Clarke and Clarke, 1985).

The prevalence of profound mental handicap is estimated to be around 1/1000 for school-age children (Fryers, 1984), although the estimate for the population as a whole is likely to be lower - around 0.5/1000 (Fraser and Green, 1991). Estimates of prevalence do vary, depending on the criteria used for defining 'profound', the age of the sample and the methodology employed in collecting the data, but all indicate that people with profound mental handicap form a tiny percentage of the general population. Nevertheless, people with profound mental handicap form a sizeable group when viewed nation-wide and it is a group which all local education and health authorities and social work agencies must take into account in their planning and provision of services.

Children with profound mental handicap - and their parents - face many daily challenges. Even basic activities such as meal times and getting dressed can be painstakingly slow and difficult and progress is inevitably made in only small steps, each taking a very long time to achieve. The presence of a child with profound mental handicap in any family imposes continuous demands and stresses on all family members. Parents, brothers and sisters have to adapt to daily routines and lifestyles which accommodate the needs of a highly dependent family member.

Many children have to cope with profound physical disabilities in addition to their profound mental handicap, many also have sensory handicaps, and epilepsy is also common. It is not unusual for a child to have profound mental handicap, profound physical and sensory impairments and epilepsy. It is estimated, for instance, by Browning, Bailey and Clark (1981) that thirty-five percent of those with profound mental handicap have severe physical impairments.

Difference versus Delay

A long-standing issue in the field of mental handicap is that of 'difference' versus 'delay' in development. Zigler (1969) proposed that development in mental handicap was the same as in normal development, only delayed: the child with mental handicap followed the same developmental sequence but at a slower rate. Discussing this with respect to language development, Rondal (1984) argues that a child whose development in different aspects of language is uneven (e.g. different levels of lexical and syntactical development), is not following the normal progression of development, even if the normal sequence of development is followed in these components. He says that in the non-handicapped child all areas of language development will be in keeping with chronological age. If development in mental handicap is similar, but delayed, the child will pass through the same stages of language development in the same order of succession, with development in keeping with chronological age across all aspects. (Rondal, 1984).

Although Zigler was not referring to those with more severe levels of handicap the debate on 'difference versus delay' has extended to this group. However, it is difficult to imagine how children with gross neurological damage could follow a normal course of development. Moreover, the possibility that development will not follow the same course in different aetiological groups must be taken into account. Different aetiologies may have genetic, neurological and biochemical characteristics that produce differences in performance (Hodapp, Burack and Zigler, 1990).

1.2.1 Level of Attainment

The American Association on Mental Deficiency defines profound mental handicap as an IQ of less than 20 or 25, with a mental age of less than three years. The American Psychiatric Association DSM-III-R Classification and the WHO International Classification of Diseases 9 also classify those with an IQ of below 20 as having profound mental handicap. It is difficult to imagine how such a low IQ can be accurately determined, especially since the testing of people with such a profound level of handicap is fraught with difficulties, e.g. testing has to accommodate the child who is blind, has no head control and who retains basic reflexes such as the asymmetric tonic neck reflex. Securing the co-operation of any child with profound mental handicap in conventional IQ test procedures is unlikely, but even if an IQ score could be obtained it is difficult to see how it could be meaningful. Mackay (1989) says that definition according to IQ level is useful in noting that a child has the most severe level of mental handicap, but conveys little else.

Descriptive definitions based on systematic observations are more helpful, offering a clearer picture of the features which characterise the children. Presland (1982) offers a description which will sound immediately familiar to parents and those who work with children with profound mental handicap:

- * virtually no speech or language development
- * non-ambulant or barely ambulant
- * very poor manipulation skills
- * absence of self-help skills
- * dependent on others for basic care

Browning, Bailey and Clark (1981) have cited similar characteristics to describe 'profound mental handicap' and the children's level of dependency is also used as criteria for classification by the National Development Team (1985). In an extensive literature review, Latchford (1989) found there to be a high incidence of physical and sensory handicaps reported, but not all had such handicaps. Most developed no speech, although some developed limited speech. There were varying levels of difficulty in learning an alternative system of communication, e.g. Makaton signs, with poor or

absent social and self-help skills. There was also a high incidence of delayed puberty and epilepsy.

Although these descriptive definitions offer a clearer picture of the child with profound mental handicap than IQ scores, they do define the children by their incapacities. In particular, they give little indication of any possible means of communication within reach of the child. Neither do they address the psychological role, function and development of emotional communication and emotional relationships. It is this aspect of development in children with profound mental handicap that the thesis will consider.

1.2.2 Terminology

In recent times, terminology describing profound mental handicap has proliferated. This is perhaps symptomatic of society's negative attitude towards those who do not conform or fit in with its ideas of what constitutes 'normal', and of the confusion of some of those working in the field about the nature of 'mental handicap'. No sooner is the latest 'label' assimilated than it is superseded by a new term. Earlier terms such as 'idiot' and 'imbecile' were, by all standards, very offensive and needed to be replaced. For some time 'mental handicap' was the accepted term (in the United Kingdom). 'The mentally handicapped' became 'mentally handicapped people', and this changed more recently to 'people with mental handicap'. The use of 'people with...' does help to emphasise and reinforce that those in question are first and foremost *people*, who happen to have a mental handicap.

Watts (1987) highlights a central point, i.e. *terminology* will not change prejudice towards people with mental handicap. The new terminology will inevitably become tainted with the old negative values if the underlying prejudices and lack of understanding remain unchanged. Those who have heard older parents use the term 'mongol' when referring to their son or daughter, will know how this word, now rarely used, can lack offence when spoken with love and respect.

The multiplicity of conditions contributing to 'profound mental handicap' cannot be succinctly described by one all-encompassing label. Amongst current terminology, the term 'learning difficulties' is especially inappropriate. Children who have profound multiple handicaps have problems which are more than just difficulties in learning, affecting almost every aspect of their lives (Ouvry, 1987). According to Mackay (1989), labelling can even be determined by geographical location - one school may label a child as having 'profound' learning difficulties, while another in a different part of the country classifies a similar child as having 'severe' learning difficulties.

Stow and Self (1989) believe that it is wrong to classify physical disabilities as 'learning difficulties'. If a child with a severe physical handicap attends a school which provides a suitable physical environment he or she may have no learning difficulties. Hogg (1991) rejects 'learning difficulties' on the grounds that the term fails to encompass the wide range of psychological processes also affected, e.g. motivation, and that it ignores the medical consequences of the extensive brain damage suffered by many. In addition, it is an inappropriate term to apply to adults.

The debate about terminology and the search for the most apt and appropriate terms will continue. The preferred term in this thesis is 'profound mental handicap'. 'Mental' is used to represent the psychological processes underlying emotional, social and cognitive development and 'handicap' is used in accordance with Bax's (1991) definition of handicap as the "social consequences of impairment and disability."

CHAPTER 2: COMMUNICATION IN CHILDREN WITH PROFOUND MENTAL HANDICAP

1. INTERVENTION AND RESEARCH

Language provides one of the most powerful means of communication (Deich and Hodges, 1977). The ability to produce sounds and think symbolically makes the acquisition of meaningful language *possible*, but it is the need to communicate that makes the learning of language *necessary* (Smith, Goodman and Meredith, 1976). However, it is vital to make a distinction between 'language' and 'communication' (Cromer, 1984), the latter being a broader category encompassing many nonverbal forms of expression and contact. Communication is a function of language, but it is also the fundamental basis for human relationships, of which language is an important, but not the sole, part.

In the normal course of development the social context is the key factor in the development of communication skills, and responsive adults sensitive to the child's actions are a key element (Bruner, 1975). Infant and caregiver form a dynamic partnership in which the infant is an able and active contributor (Trevarthen, 1990), participating through a wide range of body and vocal behaviours and expressions. The non-handicapped infant has both the motivation and the means to communicate.

In a survey of special classes in which most children were non-verbal, Evans and Ware (1987) found that less than twenty per cent of the sample used any formal system of communication. The absence of formal communication leads to major difficulties in understanding the meaning of the children's actions and vocalisations and responding to these appropriately. Referring to deaf-blind children with severe mental handicap and no apparent communication skills, Wilson (1983) suggests that aggression and tantrums arise from a failure to communicate basic needs in a socially acceptable form. Fraser (1991) suggests that some forms of self-injurious behaviours may even be primitive forms of nonverbal communication.

Many children with profound mental handicap have neither the means nor the motivation. They do not actively seek communication with others, yet without this wish or need no communication can develop (Clements, 1987). The child's motivation to communicate lies at the core of a successful interaction and intervention needs to address the lack of desire as much as the lack of skill. However, motivation in itself is still insufficient: the child needs to have a *means* of communicating that is understandable to other people.

1.1 Augmentative communication

During the 1960's and 1970's non-speech communication symbols and systems came to the fore as a viable means of communication with people with severe handicaps, and were adopted by a variety of therapists, teachers and psychologists (Lloyd and Karlan, 1984). Reid, Jones and Kiernan (1983) found that non-vocal systems based on graphic symbols and manual signing were being widely used throughout the UK in schools for children with severe mental handicap, the most common being Makaton, a system devised by Walker (1978), derived from British Sign Language.

Augmentative systems of communication aim to increase communicative competence using existing capacities, however limited, as a starting point. Using signs can affect the smooth flow of turn-taking, but it does enhance the individual's ability to communicate, providing those who care for and work with the person also understand the system (Stansfield, 1991). Constant support and teaching are essential for caregivers and others who are in daily contact with the child to ensure the system can work effectively.

However, many children are unable to master an augmentative system of communication and relevant models must be sought elsewhere.

1.2 Piagetian Framework

Piaget's sensorimotor stage offers a conceptual framework relevant to the level of development of children with profound mental handicap. The

sensorimotor period lasts from birth to around eighteen to twenty-four months. It is an important period in development, on which Piaget himself placed great emphasis (Gearheart, 1981). During this stage the child moves from purely reflex activity to an ability to think through actions required to gain desired ends.

Piaget (1954) described the sensorimotor stage as having six domains, each with six sub-stages, each reflecting the child's understanding of the world. The six domains are object permanence, vocal and gestural imitation, spatial relations, causality, means-end relationships and symbolic use of objects. The development of symbolic thought, when the child becomes able to think beyond immediate motor and perceptual events (Gearheart, 1981), is considered a pre-requisite for language (Bates, Benigni, Bretherton, Camaioni and Volterra, 1977). Uzgiris and Hunt (1975) have devised an ordinal scale of assessment for non-handicapped infants based on sensorimotor development and Dunst (1980) has developed a Piagetian-based scale for use with children with mental handicap.

Piaget believed that all children passed through stages of the sensorimotor period in an invariant order. It seems that this is also the case for children with profound mental handicap (Kahn, 1976), although Rogers (1977) found that attainments were not even across domains.

MacPherson and Butterworth (1988) found that children with severe mental handicap developed sensorimotor abilities unevenly, with greater delay in vocal and gestural imitation, object permanence and causality. The deficits in imitation were not explained by motor impairments. Moreover, the children were more seriously delayed in language and social skills than their mental age suggested. Similar findings were obtained by Kahn (1992) in a longitudinal study of 61 children with severe and profound mental handicap. Kahn believes both studies indicate that delays in the development of imitation and object permanence may cause delays in language, suggesting that object permanence and imitation are of central importance in the development of symbolism and language.

Piaget's work offers a relevant frame of reference for research and intervention with children with profound mental handicap. However, it

fails to capture the rich array of interpersonal behaviours evident in infancy and does not accommodate new knowledge about the abilities of infants, e.g. the facial imitative abilities of newborn babies (Meltzoff and Moore, 1977, Kugiumatzakis, 1985). This capacity in non-handicapped infants is remarkable, since the infants have to match another person's act with one of their own and, unlike manual imitation, there is no visual guidance, i.e. the infants cannot see their own faces in the way they can see their own hands and those of the other person (Meltzoff and Moore, 1992a). Meltzoff and Moore (1977) found that infants as young as twelve days old imitated tongue protrusion, mouth opening and lip protrusion. They obtained similar observations in a 1983 study with infants whose mean age was thirty-two hours, the youngest being only forty-two minutes old. Meltzoff and Moore (1985) consider early imitation to serve a social-communicative purpose and that it shows evidence of early social cognition.

There is no provision within the Piagetian framework to record such capacities and thus the ability of the infant can be underestimated. This risk must also be true for children with profound mental handicap. Though a helpful and appropriate form of assessment for children with profound mental handicap, it does not offer a comprehensive description of the child's communicative capacities.

1.3 Communication Assessments

Two important forms of assessment (Kiernan and Reid, 1986 and McLean and Snyder-McLean, 1987) examine communication skills within a language-learning context, both focusing on the pragmatic aspects of pre-verbal communication.

McLean and Snyder-McLean (1987) have developed a 'continuum of communicative acts' for assessing use of language and communication skills, ranging through a series of stages from reactive responses, such as smiles and cries, to the development of referential language with a vocabulary of five or more words.

The Pre-Verbal Communication Schedule (PVCS) has been developed by Kiernan and Reid (1986) specifically for use with children with profound mental handicap. The PVCS is designed to assess communicative competence using criteria appropriate to the forms of communication and expression available to this group of children. In the PVCS, pre-verbal communication skills are seen as a series of steps leading towards the development of spoken language.

The Affective Communication Assessment (ACA), developed by Coupe et al (1985) for use in schools, also offers a very useful means of recording consistent behaviours and deciphering their communicative significance. The ACA can record the idiosyncratic, but possibly meaningful, actions of the child and the context in which they occur. These forms of observation offer a positive approach, based on what the child can do, rather than what he or she cannot do.

The PVCS and ACA are particularly well suited to capturing individual forms of expression and communication within a systematic framework. Practitioners stress that the needs of the individual child must be taken into account. Teaching programmes need to be adaptable, individually tailored to suit the needs of the child (Ouvry, 1987), taking his or her personal needs and idiosyncrasies into account, including the needs of a particular day (Kiernan, Jordan and Saunders, 1978).

These assessments complement but do not address the psychological role, function and development of emotional communication and relationships. Research in developmental psychology into the development of interactions between non-handicapped infants and their caregivers suggests that insights into these aspects of development in children with profound mental handicap might be gained by studying the nature of the child's spontaneous interactions.

1.4 Studies of Interactions

Studies of interactions involving people with profound mental handicap have been sparse and few of these closely examine their communicative

abilities (Latchford, 1989). Most studies concentrate on the percentage of time spent in interactions and the proportion of the interaction time allocated to response and initiation.

Wright, Abbas and Meredith (1974) studied interactions between children with profound mental handicap and residential care staff. They found that less than seven percent of the time was spent in interactions and only two percent of these were initiated by the children. A similarly low percentage was also recorded by Repp, Barton and Brulle (1981) in both a large institution and a small group home. These studies reveal that an abysmally low occurrence of interactions, but do not provide any information about the nature and quality of the interactions that did occur, or the interactive partnership between the child and staff member.

Studies that offer a view of the effects of one partner's actions on the other are more informative. Ware and Evans (1986) found that the majority of interactions between children with profound mental handicap and teachers in special care classes were initiated by the teachers and, most importantly, that the child was rarely given an opportunity to respond. In another classroom study of children with profound mental handicap, Houghton, Bronicki and Guess (1987) noted that staff and children were using different codes to 'communicate': the staff predominantly used symbolic language, whereas the children's behaviours were non-verbal. Taking account of one person's mode of response in relation to a 'partner' highlights the missed opportunities and code discrepancies described in these studies. Detailed descriptions of the child-adult partnership can be highly informative about the strategies people employ to cope with the disruptions that occur when one partner is unable to play a full part in the interaction. This approach treats the child-adult partnership as a system.

1.5 Caregiver and Child as System

The caregiver and child with profound mental handicap form a system in which the child's responses may be delayed, jumbled and impoverished and in which the parent has to search for meaning in obscure and subtle body behaviours (Clark and Seifer, 1985). Problems of this nature can have a

serious effect, since parents may attempt to interact less in the face of lack of, or inappropriate, responses (Blacher, 1984). However, many caregivers seem to be surprisingly resilient and resourceful. In Priesler and Palmer's (1984) study of interactions between four blind children and their parents, each family was observed to have a different 'communication system', but all four shared common features, e.g. giving the children emotional feedback through the use of vocalisations or laughter, thus making their smiles 'visible' to the children. It needs only one partner to be out-of-step or insensitive to the other's behaviours and signals and the communication is disrupted and breaks down. Jones (1977) studied interactions between children with Down's syndrome and their mothers and found that either partner could disrupt the flow of the interaction if insensitive to the other's signal, e.g. leading to turn-taking clashes.

The outcome of the communication depends on the behaviours of both partners. Referring to mother-infant research, Fafouti-Milenkovic and Uzgiris (1979) propose that the mother and infant should be viewed as a social interaction and communication system, both participants forming an organised whole. By viewing the mother and infant as a system, Fafouti-Milenkovic and Uzgiris were able to detect the large contours of their interaction patterns and trace changes in these over time. Their research suggests that the system undergoes orderly change.

1.6 Significance of Idiosyncratic Behaviours

During interactions mothers respond to the infant's spontaneous actions and sounds (Schaffer, 1977). In this way interpersonal contact is developed through a naturalistic strategy appropriate to the infant's level of development and ability to participate.

Clements (1987) suggests that naturalistic strategies may help to reinforce pre-verbal forms of communication and that these strategies may sometimes need to be built round highly idiosyncratic behaviours, e.g. twirling a piece of string. He envisages such strategies leading to communicative behaviours such as pointing, gazing and leading by the hand.

Blind, deaf and motor-impaired infants are able to develop reciprocal interactions despite their disabilities (Kopp and Recchia, 1990). Kopp and Recchia describe how a blind infant might give inconsistent signals on different mornings when the mother approaches: one morning lowering the head and becoming still to detect clues that the mother is coming, another morning becoming animated at her approach. Both represent interest but are confusing for the mother if she cannot detect the pattern - unsuccessful decoding confuses the interaction. It is vital that teaching programmes that aim to develop effective communication skills in children with multiple physical and sensory disabilities focus specifically on the channels and codes of communication still available to the child in some form (Wilson, 1983).

All idiosyncratic behaviours in children with profound mental handicap, e.g. clapping, slapping on tables, should be examined for communicative significance (Fraser, 1991). Priesler and Palmer (1986) describe a mother's interpretation of her blind child's silence, observing that the silence itself seemed to be an important part of their communication:

"The mother seems to interpret P...'s silence, in combination with immobility, as signs of auditive concentration, and therefore communication. She often uses pauses and silence as a means to "make room" for P to interact." (Priesler and Palmer, 1986).

Priesler and Palmer observed several "silent" sequences such as this in their video recordings, which seemed to have a highly dynamic quality.

The significance of a given behaviour can be evaluated by comparing it in relation to other behaviours. Gleason (1988) offers graphic examples of children's attempts to make their wishes known to care staff and, very importantly, clear evidence of interactions between the children. It is a commonly-held belief, even by those who work closely with the children, that children with profound mental handicap do not interact with each other. This may be true for many children, but Gleason's work suggests we may be underestimating the children's capacity for child-child interaction: the signs are there but are not recognised. By understanding the meaning and significance of a child's behaviours, adults will be in a better position to make such evaluations.

Gleason's research supports the suggestion that the children's interactions are ordered. Using an example of a child's attempts to have a pillow removed, he describes how she uses her tongue, arms, eyes and head to indicate what she wants, persisting until an attendant removes the pillow and her goal is achieved. He draws attention to the ordered structure of her body movements and the clear beginning, middle and end to the sequence.

The ethnographic methods employed by Gleason offer an excellent means for detecting order in idiosyncratic patterns. Much research in the development of early communication in non-handicapped infants employs analysis at this level of detail. Many studies examine behaviours in even greater detail, using frame-by-frame analysis of filmed interactions, and have revealed intricate relationships between mother and infant behaviours (e.g. Meltzoff and Moore's research). During the last decade mother-infant interaction research has attracted interest from practitioners and researchers in the field of profound mental handicap as a possible model for planning intervention programmes and enhancing our understanding of the communicative capacities of children with profound mental handicap.

2. MOTHER-INFANT INTERACTION MODEL

2.1 Offering a Theoretical Model for Communication

2.1.1 Research Studies

The origins of the thesis lie in the personal experience of the author who, in 1974, began a career as a movement therapist in a hospital for people with mental handicap, a large part of this work being with adults and children with profound mental handicap. During the first two years she concentrated on establishing and developing clinical practice, keeping detailed written records of movement therapy sessions. In 1977 she first became aware of research in developmental psychology into mother-infant communication, in particular the work of Professor Colwyn Trevarthen at the University of Edinburgh. The descriptions of mother-infant interactions

immediately sounded familiar, the processes they described sounding similar to accounts she had written in movement therapy session reports.

The research work with non-handicapped infants helped to make sense of what was happening in the therapy sessions, both of the responses of the participants and the strategies she employed as a therapist. As a result of the infancy research she became interested in how nurses and other primary caregivers managed to develop their communication partnerships with the children, and the research into the normal development of early communication appeared to provide a relevant basis from which to proceed.

Support for this suggestion is offered in Browning, Bailey and Clark's (1981) study which proposes that research into the development of interactions between mothers and non-handicapped infants provides a model for the input required of caregivers with children with profound mental handicap. Research in the United States by Sternberg and Owens (1985) indicates that this does indeed offer a viable type of intervention which should be further researched. They aimed to establish pre-language signalling behaviour with school students with profound mental handicap and addressed the question of whether meaningful communication, i.e. communicative behaviour adjusted to the context of social interaction, could be developed. Sternberg and Owens adapted hierarchical procedures described by van Dijk (1965) for use with deaf/blind students; the therapist responds to the student's movements, of any kind, as if they were communicative. This teaches that movements can affect another person's behaviour and change it. This form of intervention shares similar features with mothers' responses to the communicative behaviours of their non-handicapped infants. Verbal language, though the ultimate goal, is not a necessary goal.

Kopp and Recchia (1990) suggest that it would be helpful to track the developmental course of interactions between infants with handicaps and their caregivers, using the normal development of mother-infant interaction as a framework. In this way the modes of communication available to the infant could be highlighted and development of more complex and sophisticated interaction might be assisted by appropriate support suited to the child's competency. The appropriateness of mother-infant research as

an applicable model for work with children with handicaps is also acknowledged by Hodapp and Mueller (1982).

Mother-infant interaction research has unfolded the style of interaction best suited to the infant at different stages in development. Marfo (1984) suggests that interactions between children with mental handicap and their mothers offer a way of finding out if they differ from what might be expected given the child's overall level of ability.

2.1.2 Intervention Studies

Ware and Evans (1987) describe a group of children with profound mental handicap who are particularly unresponsive. Although they may not have the severest physical handicaps, they rarely look or smile, make no attempt to play with toys and have unpredictable responses. They suggest that these children would benefit from an approach based on mother-infant interactions, given the early developmental level of the children and the evidence of infant's skills in interacting long before the development of any speech. Interactions can be developed with children with profound mental handicap based on mutual enjoyment of contact and games, e.g. turn-taking can be developed from games such as pat-a-cake (Kiernan, Reid and Goldbart, 1987).

Nind and Hewett (1988), both teachers, have developed an approach 'Intensive Interaction Teaching', which is based on early mother-infant interactions. They point to the infant's active part in the interaction and how they influence and guide the caregiver's responses as much as the caregiver guides the infant. They have developed a school curriculum for students with profound mental handicap in which Intensive Interaction forms the core.

The Intensive Interaction approach has also been adapted by Knight (1991), and a research study conducted by Knight and Watson (1990) offers a comprehensive account of the impact the approach can have on the interactions between staff and students. It reveals the value of the

communicative relationships in developing the students' abilities to initiate, take turns and understand cause and effect.

However, there is a major difference between mother-infant interactions and intervention approaches. In the normal course of development mother-infant interactions arise spontaneously, the mother's input is not a planned programme of intervention and she does not perceive a 'problem' to be alleviated. The interaction is a part of the growing relationship between mother and child; they have nothing on the agenda except to enjoy each other's company. Stern highlights the spontaneity and lack of 'agenda' when he says:

"The immediate goal of a face-to-face play interaction is to have fun, to interest and delight and be with one another. During these stretches of purely social play between mother and infant, there are no tasks to be accomplished, no feeding or changing or bathing on the immediate agenda. There is nothing even that has to be taught. In fact, if the task is to teach the infant something, he won't be able to learn what the play experience might hold for him. We are dealing with a human happening, conducted solely with interpersonal 'moves', with no other end in mind than to be with and enjoy someone else (Stern, 1977, p81)."

Knight (1991) acknowledges this difference and makes an important point when she says:

"In school settings the emphasis is always on aims, whereas in natural interaction the process is what is important, and developments grow out of the interactions (Knight, 1991, p4)."

Communication programmes more usually emphasise the structured teaching of pre-linguistic skills such as turn-taking. As Knight points out, natural interactions do occur but these are not seen as the focus for development. Eye contact is a good example. This important behaviour is often the focus of intense training, rather than creating a context in which it can naturally occur. Nind and Hewett (1988) agree, saying that although spontaneous exchanges already happen between many teachers and children with severe disabilities, they are not usually rationalised or structured. Nind and Hewett acknowledge the importance of these processes in social, cognitive and language development by bringing them to the forefront of the curriculum, taking care not to lose their natural spontaneity (Nind and Hewett, 1988).

Similar Work in Autism

Research and practice in the field of autism has also turned to mother-infant interactions as an appropriate model for planning intervention and research. Children with autism show little or no interest in social interaction (Volkmar, Burack and Cohen, 1990). Wing and Gould (1979) define the impairments of autism in a "Triad of Impairment": social impairment, communicative impairment and impairment of imaginative activity. Children with profound mental handicap are also impaired in these three areas. However, many do show an interest and willingness to take part in social exchanges, being limited by their means of expression but not by their desire. Therefore, problems in autism and profound mental handicap are not identical, but the difficult problems in social communication encountered in both groups of children has led practitioners and researchers in both fields to seek guidance from the normal development of early communication.

Christie and Wimpory (1986) propose that intervention called 'musical interaction techniques' based on early development of mother-infant interaction has much to offer in enabling the child with autism and the adult to gain shared understandings and lead the way to reciprocal interactions. In the field of research, Landry and Loveland (1988) suggest there should be research into the development of pragmatic language in autism along the lines of research with non-handicapped infants with familiar persons, and that such studies may have important implications for planning intervention programmes. This view is also supported by Volkmar et al (1990).

2.2 Applying Models of Normal Development to Clinical Populations

Extrapolating Data from Normal Development

A number of sources in research and practice have been drawn to the body of knowledge in mother-infant research to seek explanations and develop models for practical approaches. Given the developmental level of people with profound mental handicap and their limited behavioural and vocal repertoire, there does seem good reason to suggest that the normal development of emotional and social communication in infancy might offer

an appropriate model for the processes underlying their communication. However, care needs to be taken to avoid immediate extrapolation of data from existing research in normal development to a population with extreme handicaps and varied aetiology. Kiernan (1984) warns that although we might base remediation schemes on strategies observed in child development, the methods must acknowledge the age and life history of the person. People with profound mental handicap may be much more mobile, or much less, than a non-handicapped infant and will have a longer and different life experience from an infant.

Mittler (1970) stresses differences when comparing a child following a normal course of development with a child with profound mental handicap who have both reached the same stage in sensorimotor development. He reasons that the development of stage VI in a non-handicapped child of two years offers the possibility of further advances in development with the appropriate experiences. However, such a development in an older child with mental handicap means less in terms of future possibilities. It is easy to feel that there is room for considerable development when many years lie ahead, but this 'developmental' time is not infinite. The twelve-year-old girl with profound mental handicap who suddenly discovers that tilting her head produces the face stroking that she loves does not start down the rich and varied path of development seen in the non-handicapped infant who has also just discovered that his actions produce desired effects.

Hodapp et al (1990) support the view that a developmental perspective is a useful way to understand people with mental handicap and to form a basis for intervention practices. They believe that there are universal principles of development that offer insight and guidance for work with populations with handicaps. These principles concern both biological and environmental effects and change and the concepts and methodologies employed in research with the non-handicapped population and people with mental handicap: the processes of normal development can offer insight into work with people with mental handicap. This, of course, works both ways, with information collected from the population with mental handicap contributing to our understanding of the normal path of development.

Providing a Scientific Basis of Support

Practitioners have been attracted to mother-infant interaction research because it appears to offer relevant explanations and guidance in their work with children with profound difficulties in communication. However, little empirical evidence currently exists to support the validity of these assumptions. The body of knowledge in mother-infant interactions has been gathered through microanalysis of the behaviours of both infant and mother, detailing not only their frequency and duration, but also examining their temporal relationship and the performance rate of their actions. In applying the 'mother-infant' model to children with profound mental handicap it is being assumed that their interactions share the characteristics identified by these analyses. Given the gross neurological damage suffered by many children in this group this assumption needs to be verified. Latchford (1989) conducted a study of interactions in a group of sixty six children and young people and their primary caregivers (parents and residential staff) which strongly suggests that similarities do exist. Using methodology employed in mother-infant research the two studies in this thesis were conducted to gain further insights into the processes underlying the development of communication between the children and their caregivers.

CHAPTER 3: COMMUNICATION IN EARLY INFANCY

1. The Development of Early Communication

In 1902, Cooley noted that babies closely watched the movements of others and suggested that they soon recognised a connection between their actions and the changes this brought about in other people's movements. He described how a six-month-old baby, on realising that he or she had some influence over adult's movements, might attempt to attract attention by using his or her actions, such as stretching out arms, closely watching the adult's movements for the desired effect (Cooley, 1902). His observations highlighted the active nature of the baby's part in the communication.

Research by developmental psychologists has since confirmed Cooley's observations that babies play an active part in their communication with adults. Strong evidence now exists that the infant is biologically programmed to take part in interactions with other people (e.g. Bullowa, 1975; Pawlby, 1977; Trevarthen, 1977) and that even neonates can actively interact with caregivers (Bullowa, 1979; Newson, 1977; Richards, 1974). Through spontaneous rhythms of movement and expressive behaviours such as eye movements, facial movements and hand gestures, infants show sensitive responses to the communication movements of caregivers (Stern, 1985).

Mothers use active stimuli such as sounds, visual effects and contact movements like patting and rocking both to arouse and soothe infants who are very sensitive to the affective quality of the mother's behaviour. The infants may become withdrawn if handled too abruptly, or soothed by gentle actions. Mothers watch them very closely, monitoring their interest and state of arousal, fitting in their own movements and vocal behaviours to suit the infants. They generally use repetitive movements in a pattern of bursts of activity. Their actions and vocalisations are slow and exaggerated and this pattern of behaviour appears to provide optimal communication for young infants (Trevarthen, 1984). The rhythmic co-ordinations and patterns of these movements are not affected by cultural and social

influences, are found in all human social interaction, and would appear to have very deep biological roots (Newson and Newson, 1975).

1.1 The First Two Months

Meltzoff and Moore (1985) suggest that neonates are able to obtain information about the adult's movements supramodally and use this as the basis for their own physical actions. The neonate represents the adult's action through non-specific modalities, neither exclusively visual or motor. This internal representation provides the infant with a model for his or her own actions. Infants also demonstrate a remarkable capacity in discriminating and imitating the facial movements of caregivers suggesting that they can internally match a representation of their own face and others (Meltzoff and Moore, 1983).

During the first month neonates are more responsive to tactile cues and voice quality and are observed to react with a structured sensitivity when their mothers hold and caress them and to the prosody and quality of the mother's speech (Trevvarthen, 1986a). There is strong evidence of a universal timing underlying the mother's baby talk (motherese), a common timing having been observed in different languages. Cross-cultural studies have shown that adults speak differently to infants than to other adults and that the infant-directed speech shares prosodic features across cultures, e.g. slower tempo, more rhythmic (Parker-Price, Cooper, Culp and Culp, 1992). Even 7 - 9 week-old infants with English-speaking caregivers show a preference for Cantonese infant-directed speech over English adult-directed speech (Pegg, Werker and McLeod, 1992). This demonstrates not only that mothers share a common timing across cultures but that it is also shared by their babies.

Primary Intersubjectivity

Around the age of six weeks there is a marked development in the readiness of infants to engage with the speech and facial expressions of others, and at the same time their own expressions become more strongly co-ordinated (Trevvarthen, 1979). Trevvarthen (1977) describes an important development

in the infant's communication, primary intersubjectivity, which reaches its peak around the age of two months when the infant is strongly motivated to take part in face-to-face interactions. The infant appears to enjoy the interaction for its own sake, with no need for the attractions of objects. This is an emotional linking between infant and caregiver which is observable through the co-ordination of their motor engagements (Trevarthen, 1986a).

1.2 Development of Communicative Play

Towards the end of the third month direct interpersonal contact diminishes. Infants now increasingly explore their surroundings in preference to looking at the mother and no longer have the intense desire evident at two months to engage in face-to-face play. These changes accompany growth in the body and brain and correlate with developments in visual exploration and prehension (Trevarthen, Murray and Hubley, 1981; Trevarthen, 1983). Around the fourth and fifth month the infant's interaction with the mother becomes more robust and physical, with comic play and teasing. Games develop based on contingencies which provide the foundation for the fun of the transaction, as seen in the widely observed 'peek-a-boo' game.

Imitative games give opportunities for infants to develop their awareness and understanding of the relationship between self and others, and it is not always the infants who are the imitators. During social play parents are observed to provide infants with a playback of their own behaviours in imitative games and it is suggested that the baby recognises the reflected behaviours as similar to his or her own actions (Meltzoff, 1992). In the early months the mother creates interpersonal games with the infant which later become ritualised as emotional markers of their companionship (Trevarthen, 1979).

By the end of the first six months of life the baby has developed schemas of the human face, voice and touch and within these categories knows the face, voice and touch of the primary caregiver - usually the mother (Stern, 1977). He or she has mastered social cues and conventions in initiating, responding to and ending interactions with the mother and is an able, skilled participant in social interaction (Schaffer, 1977).

1.3 Sharing a Task

Secondary Intersubjectivity

Around the age of nine months the infant begins developing an awareness of the purpose of the actions of others and of symbolic movements, such as waving bye-bye (Hubley and Trevarthen, 1979). Hubley and Trevarthen describe a major development in communication around this time, Secondary Intersubjectivity, in which infants show the capacity to share a task. They show a preparedness to modify their own actions according to instructions they receive from other people and this means that they can now accept guidance on manipulating objects for an arbitrary purpose devised by others. At this age too, a fear of strangers is demonstrated and 'showing off' behaviours also increase, both when looking at a mirror image of self and in front of others (Lewis and Brooks-Gunn, 1979).

Affective Communication forms the core

By the end of the first year the caregiver's affective communication about an object regulates the infant's understanding of it (Ogan and Wladen, 1992). Cognitive development equips the infant with skills for perceiving, identifying and manipulating objects and the now well-established emotional relationship provides the infant with a means of regulating knowledge. Through co-operative activity within a known and familiar partnership, with the mother and other trusted adults, the baby develops an ability to understand and act on objects with meaning and intentionality (Trevarthen, 1986b).

1.4 The Importance of Familiar Communication Partners

Stern describes the end of the first year as a period of 'intersubjective relatedness'. One-year-olds participate in a new range of communications that need the supportive attention of adults. While these communications are more skilled they are also more dependent on the interested support and responses of others. At this stage in development, many of the infant's communication signals are idiosyncratic to the individual child and to the individual family. The signals are effective because they have evolved

within and through the many interpersonal encounters with a familiar communication partner who is able to immediately recognise their meaning. Obviously, strangers do not have this historical knowledge and cannot offer the same support.

This is also observed in deaf infants for whom a deaf sign language is the normal means of communication. As well as understanding the specific meanings of certain hand signs, they also reproduce rudimentary forms of hand signs which have become important to them through co-operative play (Goldin-Meadow and Feldman, 1977). Proficient adult signers using the same language do not usually recognise these rudimentary signs. The signs are distinct and are used appropriately and with intention, but they are protolanguage versions which can only be understood by a familiar caregiver.

Attachments

Infants quickly form attachments with their caregiver (Bowlby, 1969). In secure attachments the infant feels the caregiver to be readily available and sensitively responsive to his or her needs (Ainsworth, Blehar, Waters and Wall, 1978), being reassured by the mere presence of the caregiver. From this secure base the infant begins to explore the environment, leading to a developing awareness of his or her separateness and autonomy. During the second half of the first year, infants do not smile at strangers as readily as before, and some show a fearful reaction (Morgan and Ricciuti, 1965). Morgan and Ricciuti observed that babies in small families who seldom saw strangers were no more likely to be upset by a stranger than babies who had contact with many people. The fear shown towards strangers by non-handicapped infants who are on the brink of task sharing seems to represent some kind of heightened awareness in the infant of the dependence of this kind of shared communication on familiar, well-known figures (Trevvarthen, 1986a).

The infant is an active partner in social exchanges by the end of the second month, but it is not until the end of the first year that he or she is actually aware of the two-sided nature of interactions. The baby learns that dialogues are two-sided, based on roles that are reciprocal and

interchangeable, e.g. listener/speaker, giver/taker. Action patterns of a joint nature, as in give-and-take games, cannot appear until the infant has mastered reciprocity (Bruner, 1983).

The development of language is related to the infant's ability to participate in interactions during the first year of life (Bruner, 1974) and this places the acquisition of language firmly within a social setting (Schaffer, 1977). Infants also form their first relationships through non-verbal interactions and through these relationships begin to learn about the world around them (Bullowa, 1979). Therefore, these early exchanges are important in laying the foundation for the development of interpersonal relationships (Stern, 1985).

Coactive Exchanges and Sharing

Coactive exchanges are common between non-handicapped babies and their caregivers, but are rarely found in interactions between non-handicapped adults (Beebe, Jaffe, Feldstein and Alston, 1985). Stern (1985) has a category for analysing mother-infant interactions which he has called "interpersonal communion", referring to the mother 'sharing' or being 'with the baby'. During interpersonal communion the mother is not trying to influence or change what the baby is doing. Rather, she is participating with and sharing in the baby's experience without attempting to alter his or her behaviour. The mother reflects and empathises with the baby's affective state rather than imitating what he or she is doing.

Nonverbal communication does not require the participants to take turns in the way that verbal communication does. In verbal conversations it is difficult to attend to what the other person is saying and to speak at the same time, but there is no such conflict in processing the other person's smile and smiling back at the same time. Thus, the mother's and baby's non-verbal behaviours can co-occur without interrupting each other's flow of communication, e.g. the baby smiles, while at the same time the mother mirrors or exaggerates the smile without encroaching on his or her turn.

Bavelas, Black, Lemery and Mullett (1985) have investigated a phenomenon they term 'motor mimicry' in which a person assumes movements and

postures that are empathetic with an observed other, e.g. showing a strained facial expression and physical tension while watching someone lifting a heavy weight, or flinching when seeing another receive a heavy blow. This, they believe, provides physical evidence of taking the role of the other. Mothers have been observed to open their own mouths while spoon feeding their babies (O'Toole and Dubin, 1968, cited in Bavelas et al, 1985). The mother was observed to do this after the baby, confirming that she was indeed copying and not attempting to encourage the baby to follow her lead.

Negayama (1991, personal communication) also observed this same behaviour in Japanese and Scottish mothers in a cross-cultural study of infant feeding. Bavelas et al suggest that while such behaviour may not necessarily be expressing internal states, it is expressive *to* the other person. The mimic is giving a momentary portrayal of feeling like the other, as if actually in the other's situation. The analogic coding of non-verbal behaviour is especially suited to expressing the emotional quality of human relationships in a way that is not possible through the digital coding of language (Danziger, 1976).

Much of the infant's activity during the first eighteen months is social and communicative. Very early on in life this develops from an initial biological attachment into a reciprocity which is sensitive to both the infant's idiosyncratic actions and to cultural practices (Bruner, 1983).

2. Rhythmic Nature of Mother-Infant Communication

Infants actively seek regularities in the world around them and their actions and responses are co-ordinated with those of their caregivers: "infants are tuned to enter the world of human action" (Bruner, 1983). Komisaruk (1982) believes that the spontaneous rhythms of human movement are related to biological rhythms and suggests that they provide a rhythmic reference for linguistic and interpersonal expressions. The temporal beat provides predictability, allowing the participants to follow the flow of interaction in which each person's actions make sense to the other, with each fitting in their actions within a temporal framework which is the same for every

encounter, whoever and wherever it takes place. The evidence is strong that communicative timing is pre-wired, equipping the infant for immediate contact with other humans.

The study of the co-ordination of behaviour in social interaction is strongly influenced by the descriptive work of Birdwhistell (Kendon, 1982). He has focused on the function of body motion in communication, looking at the part it plays in the interaction rather than its possible expression of inner states (Kendon, 1972). Researchers using this approach, such as Condon and Ogston (1967) and Kendon (1972; 1973; 1982), have studied ways in which non-handicapped adults co-ordinate their behaviours in complex dance-like patterns when engaged in interactions. Key (1980) calls these synchronies 'conversational rhythms' and 'inner, idiosyncratic rhythms'.

2.1 Co-ordination of Movements

It is a popular misconception that the movements of infants are unco-ordinated. Certain aspects of co-ordination in physical development, e.g. hand-eye are not present at birth, but the finely-tuned co-ordination of expressive movements *is* found (Schaffer, 1977). Condon (1979) noted how, in adult communication, a person's body movements were in precise synchrony with his or her speech and that the listener also moved in synchrony with the speech. This co-ordination is also seen at the time of birth. Condon (1979) found that babies who were only twenty-minutes old synchronised their movements with human speech, but not with regular, inanimate sounds. It is difficult to imagine how babies could learn to do this in such a short time and it is likely that this synchronisation is an innate capacity.

Peery (1980) found that the head movements of caregivers and neonates are co-ordinated in face-to-face interactions, suggesting that such sensitivity so early in development is largely innate. In a study involving one hundred infants, Jaffe et al (1990) discovered that interpersonal timing of vocal behaviours was present in all infants both with their mothers and with female strangers who were experienced in playing with babies. Jaffe and his colleagues believe this co-ordination is suggestive of a social-perceptual

capacity which is biological and robust. Each adult and infant influenced the other in the interactions, this being evident even with babies as young as six weeks, although the mutual influencing was asymmetrical as one might expect with one immature partner.

Microanalysis reveals that mother and infant co-ordinate with timing precise to a fraction of a second (Beebe, 1982), and that adult communication signals have a tempo and organisation very similar to the spontaneous tempo and organisation of infantile movements (Trevvarthen, 1986a). The structural features of these movements can be discerned even when there is no possibility of the infant being paced by an outside source (Trevvarthen, 1984).

2.2 Temporal Intervals

By around the age of three months the infant is able to predict the timing of the mother's communication behaviours, these normally occurring in rapid succession (Campbell, 1986). The infant displays a remarkable ability to keep track of this rapid stream of behaviours, suggesting that the baby is anticipating, not reacting, to the behaviours. In most mother-infant engagements the time between the onset and offset of the mother's and infant's behaviours is too short to fall within the limits of known reaction times. Communication between two people is not a simple chain of 'action and response'. Rather than following each other in alternating turns, the actions of the participants frequently overlap and give the appearance of following a shared programme (Stern, 1977).

Using the analogy of a waltz, Stern (1977) illustrates how the leading partner uses non-verbal prompts such as hand pressing and body inclination to indicate the direction to turn. When the other partner responds to this they are both able to follow the familiar dance steps until it is time to change to a new direction. The more the partners are used to dancing with each other, the longer their sequences can be, having less need for leading and prompting.

Disruption of Timing

When response and stimulus are synchronised, both appear at the same time. It is necessary to be able to anticipate the signals in order to synchronise and for this they need to be periodic - the *signal* is not the stimulus, but the *temporal interval* between each signal (my italics) (Fraisse, 1982). Infants react adversely when anticipated temporal signals from the mother are disrupted. Murray (1980) conducted an experiment in which two-month-old infants watching video recordings of a happy engagement with their mothers thirty seconds after it was recorded showed immediate confusion and distress. Similarly, mothers watching briefly delayed recordings of their infants communicating, though not detecting that the recordings were not live, were aware that there was no real contact. They felt the 'communication' to be odd and unsatisfactory.

In Murray's examples the actions themselves were communicative, but they were being performed at the wrong time, failing to dovetail with the other's performance. Thus if the mother expresses a positive behaviour which is unrelated to the baby's expressions, its positive nature is insufficient in itself to engage the infant. In such circumstances the infant will be seen to show distress and discomfort. Infants are able to detect that the mother's behaviour does not fit in with their actions because they are able to make precise predictions about when she should respond (Trevarthen, 1986a).

Maternal Looking Patterns

Schaffer (1977) describes the looking patterns in mother-infant dyads as being very different from those found in adult dyads. The timing is essential to the smoothness and continuation of the interaction and so the mother has to hold herself in constant readiness to intervene at appropriate moments. Thus much time is spent visually attending to the baby. There is a constant monitoring so that she can synchronise her interventions with what the baby is doing - the *when* of her intervention is as important as the *how*.

2.3 Pacemaker for Rhythmic Communication Movements

2.3.1 Heartbeat

What acts as the pacemaker for the rhythmic behaviours of the caregiver? There is a popular belief that the heartbeat is the underlying influence on maternal behaviours, especially those which have a soothing effect, e.g. rocking a baby to sleep. The notion that the sound of the heartbeat soothes babies is dispelled by Schaffer (1971) and Hargreaves (1986), who both cite conflicting research results by Salk (1962) and Brackbill, Adams, Crowell and Gray (1966). Salk concluded that heartbeats did have a greater effect, while Brackbill et al found the sound of heartbeats to be no more calming than a metronome or a lullaby.

Salk played a sound similar to a heartbeat to newborn infants for four days and found that they cried less and gained more weight than a control group. His conclusion was that infants became imprinted on the mother's heartbeat while in the womb. Brackbill et al presented the infants with four conditions - no sound, heartbeats, metronome and lullaby - finding no differences between the sounds in measures of motor activity, heart rate, respiration and crying. A difference was found, however, between the presence and absence of sound. Salk's failure to include other auditory controls led to a wrongful conclusion about the effect of heartbeat (Schaffer, 1971).

Morris (1979) links certain aspects of the calming behaviours used by mothers to the heart rate, e.g. gentle rocking, pacing up and down while cradling the baby in her arms. He believes the reason for their calming influence lies in the way the actions follow some of the rhythms the baby experiences in the womb, e.g. re-creating the swaying movements the baby felt as the mother walked about. However, Morris points to there being a problem with this comparison. Mothers rock their babies and pace about with them at a *slower* rate than their normal rate of walking, the latter reported to be around 110-112 steps per minute (Fraisie, 1982). Although these actions may help to soothe the baby by copying the motion felt in the womb, the differences in the *rates* of movement still need to be explained.

Morris describes an experiment using a mechanically operated cradle to determine the optimal rocking speed for calming. Movements at very low or high speeds had little soothing effect, but when the speed was set to 60-70 rocks per minute - similar to typical maternal rocking and pacing rates - the babies were immediately soothed. Morris also notes that the recorded sound of the heartbeat has a soothing effect on babies if played at the normal rate, but not if played at the usual walking rate (Morris, 1979), and concludes that the *rate* of the heartbeat soothes and calms the baby.

Komisaruk (1982) cites a study by Lourie (1949) of a group of 130 children in a paediatric clinic, in which twenty percent exhibited rhythmical body movements such as rocking, rolling and swaying. Lourie's conclusion was also that the heartbeat was the pacemaker for the majority of the children, and the breathing rate for the remainder.

Linking heart rate to the calming effects of maternal behaviours is a seductive theory, but it is an argument that is difficult to sustain. Sachs (1953) adds a note of caution to the belief that musical tempo was originally based on the pulse beat. He cites his own pulse rate, which was generally in the sixties and sometimes lower, as an argument against this notion. The heartbeat varies so much between and within individuals, depending on a variety of factors such as age and psychological state and can be changed quickly by events such as a sudden fright. Not only is there a wide range of resting pulses, e.g. one person's resting pulse may be in the low sixties while another's lies in the eighties, but the individual resting pulse can also vary considerably at different stages in a person's lifetime, e.g. an increase or decrease in fitness, and even within the same day, being slower at night and speeding up during the day. Heart rate does not supply a stable entraining agent for the pace of caretaking behaviours.

2.3.2 *Brain Rhythms*

It seems more probable that the tempo of communication movements is driven by brain rhythms. In analyses of films from a variety of cultures, Byers (1979), an anthropologist, found rhythm sharing to be a regular feature of interpersonal and group behaviour. In his observations the

rhythms of communication movements appeared to fit in with the frequency of an underlying biological rhythm of ten cycles per second, a rhythm also found by Sollberger (1965). Byers believes these interpersonal rhythms to be a universal of human communication. He concludes that the biological rhythms underlying speech and movement behaviour provide temporal building blocks for behaviour which is then shaped by the culture in which the child grows up.

However, it seems very unlikely that there is one neurological master clock which operates all the physiological and psychological body rhythms - it is much more probable that there are many such neurological clocks, some inter-related to varying degrees and some completely independent (Campbell, 1986). It is suggested by Beebe, Stern and Jaffe (1979) that the caregiver's vocalisations and body movements form the zeitgeber for communication rhythms, entraining the endogenous rhythms of the infant. Perceptual rhythms in the infant's brain are entrained by the rhythms of the mother's expressive behaviours. In other words, the mother entrains the baby's nervous system with her play.

3. Mother-Infant Interactions as an Appropriate Model

During the first twelve months of life non-handicapped infants proceed through a remarkable series of rapidly changing developments, in all aspects of which they are active participants. It is clear that affective communication with the mother (or primary caregiver) lies at the core of the processes through which non-handicapped infants have attained these developments. Sound foundations for future language and cognitive development are laid down in the interactions between infant and mother in the early months of life. By the time non-handicapped infants enter the second year they are well in advance of many children with profound mental handicap in every aspect of their development, but it is clear that rich and expressive communication is possible long before the major milestones in the second year are reached.

The development of early mother-infant interactions appears to offer a relevant model for understanding the nature of the communication between

children with profound mental handicap and their caregivers. This is not to suggest that a period in normal development should be taken and applied without modification to an older group with profound handicaps. Rather, it is being advocated that the *style* of communication adopted by adults when they are communicating with non-handicapped infants and the way in which the infants participate may give useful guidance for understanding and explaining communication styles in children with profound mental handicap. Thus, research in early development appears to provide a relevant basis from which to proceed and explore this link.

3.1 Introduction to the Research Studies

The descriptions of mother-infant communication and methods of data collection and analysis developed by Professor Colwyn Trevarthen and his colleagues at the University of Edinburgh form the basis for the methodology. The research is divided into two studies, each contributing different, complementary aspects to the study of communication and relationships between children and young people with profound mental handicap and their primary caregivers.

Study 1 examines interactions between children with profound mental and multiple handicaps and their caregivers. Study 2 compares the communicative involvement of young people with profound mental handicap during short encounters with their caregivers and two different groups of strangers. The two studies share many methodological features. The procedures for each study are described separately, with those common to both being described in Study 1.

The two studies are presented separately in Chapters 4 - 8; in Chapter 9 the findings on a phenomenon common to both studies is presented and discussed; and in Chapter 10 the findings of the two studies are discussed.

CHAPTER 4: STUDY 1

METHOD

Study 1 aimed to provide descriptions of the ways in which children with profound mental and multiple handicaps (PMMH) responded to and initiated communication and the strategies used by adults to elicit and sustain communication.

1. SUBJECTS

1.1 Identification and Selection

There were 12 PMMH subjects, aged 8-18 years. Six, three boys and three girls, lived at home and the other six, again three boys and three girls, were resident in a mental handicap hospital. Subjects were selected with the assistance of social work agencies, hospital nursing staff and a member of a parents' association.

The family background of the six children living at home reflected a mix of family circumstances. One mother was herself disabled by a very severe visual impairment, having only tunnel vision in bright lighting conditions and no vision in dim lighting.

The family home and institutional care settings were chosen as two principal environments in which children with profound multiple handicaps resided at the time of the study¹. There were no younger children resident in the hospital in which the study was based, and recruitment was confined to a comparable age range between the two groups. The interactions themselves were the focus of study, and the range of opportunities afforded by the two environments for communicative contact were not examined.

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¹This refers to local circumstances at the time of recruitment. Since the completion of the project there have been no new admissions of children to long-term hospital care in the location of the study.

1.2 Selection Criteria

All subjects were classified by the agencies concerned with their care and education as having profound mental and multiple handicaps. However, the essential criterion for this study was that the subjects were functioning at a pre-symbolic level of development, with no formal system of communication - they had not developed language and were unable to use a manual signing system or technological aids to communication. In addition to their profound mental handicap, all subjects had profound physical disabilities. Every child was dependent on others for basic care, requiring total assistance with feeding, dressing and personal hygiene. Four were blind, one of whom had a severe auditory impairment, and eight suffered from epilepsy.

Within the above criteria, the subjects were randomly chosen from the names offered by the agencies. They were considered typical of the most severely disabled of the population with profound mental and multiple handicaps.

Individual children participating in the study

Greig (aged 8 years): Greig had a very restricted range of movement. He did have a degree of head control, but was unable to sit unassisted and had to be carefully supported in positions best suited to his physical disabilities. Nevertheless he could be very active and was very reactive to people and events around him. He displayed looks, smiles and sounds and used a number of idiosyncratic actions to make his wishes and needs understood.

Susan (8 years): Susan was blind. She had poor head control and was unable to sit without assistance. Though not an active child, she was generally alert and responsive to others, although she did have quiet moods when it was less easy to engage her attention. Susan displayed a wide range of sounds, smiles, small movements of her body and oriented her body towards others.

David (9 years): David was very floppy, had poor head control and very poor control of his movements. He was alert and responsive to the events around him. He reacted immediately to attempts to engage his attention and clearly enjoyed the company and attention of others. David displayed smiles, looks and sounds and occasional bursts of body movements.

Linda (10 years): Linda was blind. She had good head control, but was unable to sit unaided. She reacted readily to other people, especially when they were in close physical contact, and seemed to enjoy the 'hustle and bustle' around her. Linda displayed sounds, smiles, occasional bursts of body movements and oriented her body towards nearby adults.

Steven (12 years): Steven was unable to sit without assistance, but he was very active and mobile, able to move quickly round the room on his back, using a 'shuffling' action. Whether or not he reacted to others depended on his mood. If he was pressurised to show a response to attention, he quite often pushed the other person away. He had repetitive hand mannerisms that intensified when he was in a 'withdrawn' mood. Steven displayed body movements, looks, smiles and sounds and used a number of idiosyncratic actions to make his wishes and needs understood.

Jane (13 years): Jane was able to stand and walk with assistance. She could shuffle and roll round the room at speed and, when in an active mood, offered a 'moving target' to those who wanted to gain her attention. She was generally alert and reactive to events, though she did sometimes have quiet moods when she seemed to 'switch off'. Jane displayed smiles, looks, sounds and body movements and used a number of idiosyncratic actions to make her wishes and needs understood.

Sheila (14 years): Sheila had poor head control and had to be carefully supported when sitting. She was inactive, with a very restricted range of movement. There were certain times of the day when she was more alert, e.g. late morning. She was often very lethargic in late afternoon and it was very difficult to gain her attention during these periods. Sheila displayed smiles, looks and sounds and sometimes turned towards nearby adults.

Colin (16 years): Colin was able to sit well with appropriate support and had good head control and he was capable of using strong body movements. His mood was generally stable, showing no extremes of activity or withdrawal. His attention did sometimes become fixed on objects, e.g. bright lights, and it could be difficult to divert his attention away from them. Colin displayed smiles, looks and sounds.

Julie (17 years): Julie was blind and had a severe hearing impairment. She had good head control and was able to sit well with support. She was mostly inactive, using only small body movements. She was generally more alert in the morning, although her different levels of arousal were not so marked as in the case of Sheila. She did not react to people or events unless they were very close to her. Julie displayed smiles, sounds and small movements of her body and turned her body towards others who were close beside her.

John (17 years): John was able to sit unaided. He could also shuffle a short distance along the floor, although he only moved around occasionally. He frequently manipulated objects and certain toys seemed to attract his attention. He was usually more alert in the early afternoon. He was very lethargic before the onset of an epileptic seizure. John displayed smiles, looks and body movements, touched others, and turned towards nearby adults. He used a number of idiosyncratic actions to make his wishes and needs understood.

Mark (18 years): Mark was blind. He was able to walk short distances, though his balance and quality of walking was poor. He often sought out the company of others and sometimes became angry and upset when a period of play had to finish, or if it was not possible for an adult to immediately respond to him. He was sometimes self-injurious when upset, violently slapping his head and face and biting his hands. Mark displayed body movements, smiles and sounds and used a number of idiosyncratic actions to make his wishes and needs understood.

Cathy (18 years): Cathy had poor control of her movements and could not sit without strong support. She reacted to others, usually for short periods at a time. She often watched the events around her, even when she was being unresponsive to the overtures of others. Cathy displayed smiles, looks, sounds and small body movements and used a number of idiosyncratic actions to make her wishes and needs understood.

1.2.1 Obtaining Consent - Children at Home

Mothers were first approached by a professional worker or another parent well-known to them, to enquire about their willingness to participate and to obtain permission for the researcher to contact them. On giving this consent the mothers received a telephone call providing further information about the project. Following their verbal affirmation to participate, they were sent an information sheet and consent form. The first video recording session was arranged on receipt of written consent. All those approached agreed to participate in the project.

1.2.2 Obtaining Consent - Hospital Residents

Permission to conduct the research (Study 1 and Study 2) within the hospital was first obtained from the hospital management group who vetted and approved the selection procedures and the methodology. The parents of children were then contacted by a member of the nursing staff who knew them well. The project and the nature of their child's proposed involvement was fully explained and their permission was obtained to send an information sheet and consent form. Again, video recording did not begin until signed consent was received. This procedure was conducted smoothly, with only one parent declining permission.

1.2.3 Ethical Approval

The procedures for contacting and informing parents about the project, obtaining consent, safeguarding confidentiality and the research methodology were approved by a Health Board Ethics of Research Committee prior to the start of the research. It was emphasised to parents and hospital caregivers that filming during a recording session would be stopped at any time they wished and

that any material they did not wish to be used would be deleted. In the event there were no such occurrences.

2. PROCEDURE

Data were collected by video recording the PMMH subjects with a parent or nurse. This provided a permanent record which could be viewed repeatedly at normal speed and in slow motion, allowing episodes of communication to be identified and described in detail.

2.1 Video Recording;

2.1.1 Timetabling

Communication with children with profound mental and multiple handicaps can be very difficult to initiate. To improve the chance of recording communication, filming took place on a minimum of four occasions at intervals of four to six weeks between sessions. The time of day was arbitrary, having to accommodate the child's school and therapy timetable, the caregiver's commitments and the child's patterns of alertness.

The six children living at home were filmed with their mothers four times at home and on four occasions in a specially designed studio in the mental handicap hospital. This allowed recordings in familiar surroundings as well as in the better filming conditions of the studio. No differences in the responses of the subjects were noted between the two settings.

The six children who were hospital residents were filmed on four occasions in the studio, which was situated near their unit, each with a member of the nursing staff (4 women and 2 men) well-known to them. The child-nurse pairs were selected by the staff, who agreed unanimously that the pairs represented the closest

relationship between each child and a member of the nursing staff. Recording sessions lasted from 10 to 20 minutes, depending on the child's mood and wakefulness. Communication episodes were obtained from all child-caregiver pairs.

Recording sessions for the hospital residents had to be fitted around the staff's ward duties and it was necessary for the timetabling of sessions to be flexible, to cope with changes at very short notice on the day in question. The researchers were based at the hospital on recording days to allow such changes to be made easily. A small number of cancellations were necessary when children were unwell or there were staff shortages, but it was possible to arrange alternative sessions for all of these.

It was easier to vary the session times for the hospital residents than for the children living at home. The hospital children were already on-site and it was possible to organise their sessions to fit in with their school day and therapies. Timetabling visits by the children living at home involved special transport arrangements, and a half-hour drive to the hospital through congested traffic at peak travel periods was required for most children. The majority of children were filmed after school in late afternoon, but all were filmed at least once at a different time during holidays and at weekends. Again there were a small number of cancellations when children were unwell, all of which were re-scheduled.

The sessions were cancelled if a child had an epileptic seizure earlier in the same day, or discounted if a seizure was reported to have occurred after the session. Though seizures were infrequent, it was important to take account of their occurrence since they could affect the children's level of response.

2.1.2 Procedures in the Studio

Studio recording took place in a quiet, comfortable room with a large wall mirror, some toys, a soft playmat and several chairs. The

room was fully carpeted and all walls were covered by curtains to assist the quality of sound recording. Beige curtains provided a neutral backdrop for filming. The caregiver was asked to communicate with the child as he or she usually did when they had some time to spend together. No set procedures were stipulated. Many of the mothers brought a drink or snack for their child since most were used to having some form of refreshment at the time of day they were being filmed. All caregivers were free to bring toys into the session.

The hospital studio and recording system was specially designed for these studies. The recordings were made by two cameras. One automatic-focus camera was fixed high on a wall in the studio on a pan and tilt unit which was operated by remote control from an adjacent recording room. In this room a second camera filmed through a plain safety-glass window with only the lens visible through curtains. A wall-mirror opposite the second camera gave additional filming angles. Two high quality microphones were fixed on the studio ceiling, connected with an audio mixer in the recording room. The cameras were connected to a video mixer, allowing a smooth transition between camera pictures and, where necessary, split-screen filming. Each camera and the video recorder were linked to a separate TV monitor, allowing a simultaneous view of each camera picture and the picture selected for recording on the videotape. This arrangement maximised the possibility of recording events clearly wherever the child-adult pairs moved in the room and whatever their orientation. Recording was carried out by the researcher and a research assistant.

Both child and caregiver were kept within the recorded camera frame where possible. The remote controlled camera in the studio had a fixed lens which was set at the mid-point of its focal length to allow subjects to be tracked round the room, at the same time obtaining a suitably close view of their actions for analysis. The principal camera was in the adjacent recording room, providing close-up and wide angle coverage. The close-up was used to give as detailed a view as possible of the child and caregiver, but care was

taken to avoid zooming in to specific actions to the exclusion of other concurrent events. Split-screen filming was used when one subject had his or her back to the camera in a position that blocked out any view of his/her actions, or when child and caregiver were too far apart to be captured by one camera. Securing an effective picture of the communication was rarely difficult as the children's physical disabilities severely restricted their mobility and most pairs remained within a small area of the room, the majority of caregivers preferring to remain on the play mat.

No attempt was made to conceal the cameras from view, but they were unobtrusive. The caregivers were shown the set-up in the studio and adjacent room before filming began and given a demonstration of the two-way camera system. All reported that they quickly became used to the presence of cameras, especially as they became more involved with the children. The hospital staff felt that the children responded in typical ways during the recordings, but that they recognised they were in a strange room. Though the room itself was new to the children it was only a short distance from their unit, reached via familiar surroundings. The children living at home had to contend with a lengthy journey, totally new surroundings and a break in their familiar routine. However, the mothers also considered their child displayed a typical range of responses and mood, while at the same time showing an awareness of being in a new place.

2.1.3 Recording at Family Homes

The filming in the homes of the children was carried out using the smaller of the two cameras, a portable video recorder and an external microphone. The filming sessions lasted for the same period as in the studio (10-20 minutes). The visits themselves lasted longer, depending on many factors, e.g. whether the child had been delayed on the journey home from school, mother attending to other children. All children were filmed in situations normal to their daily routines. For most this included a period of greeting and

a 'chat' and having a drink or snack. Mothers reported that they were very aware of the camera at the beginning of the first session, but by the end of the session were feeling more relaxed about its presence, and they gave it little attention in subsequent visits.

During filming some mothers occasionally spoke to the researcher, who always responded conversationally. In the first visit most sought, and were given, reassurance that what they were doing during the recording session was appropriate. The majority of subsequent remarks were comments on the children's actions, e.g. 'He always laughs when I do this.'

Chatting to the mothers before and after filming seemed to help them feel more at ease, also giving an opportunity for the researchers to show their interest in the children. This had important consequences - several mothers reported that during the first home visit they had monitored the researchers' responses to their child to assess their concern and interest.

The closest possible full-length view of both mother and child was kept in the camera frame. The children all required physical support because of their severe physical disabilities, effectively confining their activity to a small area of the room well within the range of the camera lens. On the infrequent occasions when a child was left alone for a moment, e.g. to fetch a drink, the camera focused on the child and recorded the greeting between mother and child on the her return.

2.2 Video Reviews with Mothers

Video reviews were conducted with five mothers after completion of the main analysis. The sixth mother had moved from the area. The reviews were conducted individually within the Department of Psychology to allow the use of an industrial video playback recorder and large TV monitor, giving a large, clear TV image. The mother who was visually impaired was able to discern a sufficiently clear

image by sitting extremely close to the screen in bright lighting conditions.

The procedure for video reviews was an adaptation of Buck's (1984) segmentation technique in which viewers watching a behavioural sequence on film are asked to press a button when they judge "something meaningful" to occur. This procedure allowed the mothers to make instinctual judgements about the behaviours they found to be meaningful, based on their subjective knowledge of their child. Mothers were asked to watch one recording session and to indicate when they felt their child was aware of their presence or was responding in some way, and the beginnings and endings of their selections were noted. They were asked to view the recordings a second time and describe the parts of their child's behaviour that indicated he or she was aware or unresponsive. In addition, they were asked to estimate the child's level of involvement in what was happening. Awareness and involvement were rated according to the following definitions:

Aware

The child is a spectator. He/she shows awareness of his/her mother or gives her some attention, but does not get involved in what she is doing.

Involved

The child is a passive participant. He/she responds to what his/her mother is doing with actions and sounds, e.g. smiles, vocalisations, reaching out, turning head towards mother.

Very Involved

The child is an active participant. He/she not only responds to the mother, but plays a part in keeping the interaction going, or initiates contact.

An example of a review session is illustrated in Table 4.1. The first line of each pair of counter numbers refers to the onset of some form of awareness and the second to termination of contact or a change in level of involvement. The corresponding text refers to the on/off cues identified by the child's mother. The example shows different levels of continuous communicative contact within a segment of a recording.

Anecdotal Information. At the end of the review session the mothers were asked for general information about the ways in which their child communicated, providing a more extensive description about each child's general form of communication. Staff changes and other unavoidable circumstances prevented a similar follow-up being conducted with the hospital caregivers.

Table 4.1 Extract from a Review Session

Involvement	Counter Nos.	Cues
Involved	<u>hr min sec msec</u> 0.00.19.61} starts 0.00.50.13} ends	*lifts head towards mother *head starts to go down, closes eyes- means child is less involved
Aware	0.00.50.13} starts 0.00.52.65} ends	*‘Closed eyes’ cue reduces level to ‘aware’ *eyes are open wide - means child is more involved
Involved	0.01.52.65} starts 0.02.34.69} ends	*‘Open eyes’ cue raises level to ‘involved’ *eyes open very wide- means child is even more involved
Very involved	0.02.34.69} starts 0.04.15.77} ends	*As well as ‘wide eyes’, child also moves hand, tenses body, keeps turning head towards mother, smiles *recording fades out

3. CODING AND ANALYSES

As the PMMH subjects had no formalised system of communication, the first task was to compile a coding schedule which was capable of adequately reflecting and distinguishing their highly individual forms of response. In all analyses the communicative behaviours of both child and caregiver were examined.

3.1 Development of Coding Schedule

A survey of all 72 recordings was conducted to obtain an overall view of how the PMMH subjects and their caregivers communicated. Through repeated observations, descriptions were obtained of the ways in which the children responded to their caregivers and of the behaviours which were typically used by caregivers to elicit and maintain communication. Observations were categorised under headings which could accommodate individual differences, (e.g. 'gestural action' covered a variety of different movements used by children for similar purposes) and coding schedule, *Interactive Behaviours*, was compiled from these categories. The schedule contained twelve categories for caregiver behaviours and ten categories for child behaviours.

Physical contact used in communication was categorised under one of four possible headings for caregivers ('hand/body,' 'specific actions', 'moulding', 'body games') and one of three headings for children ('hand/body', 'gestural action', or 'moulding'). The same physical behaviour could be categorised under one heading only. The categories excluded actions providing physical support, (e.g. supporting a child in an upright position), or resulting from physical handling, (e.g. a child's hand dropping to rest on a caregiver's knee when he or she was moved into a different sitting position).

The category headings are displayed in Table 4.2 and the full coding schedule is included in appendix 1.

Filming procedures did not permit a highly detailed analysis of facial expressions. The faces of the caregiver and child were not always in close enough view to obtain a consistent record of the more subtle changes in expression and, therefore, only marked expressions were noted. Clear smiles were coded separately. 'Facial movements', (e.g. widening an open mouth), which the children sometimes made, were easier to detect on screen. The caregivers normally held a pleasant, neutral expression when attending to the

child. When they did change their expression clearly enough for the camera to capture, it was usually an exaggerated form of expression made to catch the child's attention or to provide amusement, e.g. pretending to be hurt.

Table 4.2 Coding Categories

Adult	Child
Hand/Body Contact	Hand/Body Contact
Specific Actions	Gestural Action
Monitor	Orient
Moulding	Moulding
Smile	Body Movements
Facial Expressions	Body Stirring
Look	Smile
Facial Closeness	Facial Express./Movements
Body Games	Look
Games with Toys	Vocalise
Sing	
Vocal	

3.2 Transcription and Analyses

3.2.1 *Transcription of Videotapes*

48 episodes of 'interaction' were analysed and compared with 48 episodes of 'non-interaction'.

First, twelve episodes of 'interaction', in which the child's behaviours appeared to be directed towards the adult, were initially selected for each child-caregiver pair. The following criteria had to be fulfilled:

1. One or more body or facial actions or vocalisations were prompted or changed by the caregiver's interventions, e.g. when a caregiver patted a child's hand he stopped moving his limbs, held his body still for a moment then vocalised. The response had to occur within five seconds of the caregiver's intervention.

2. There had to be two consecutive phrases of response. For example, the response described above would have to be followed by another phrase, such as a second vocalisation, or body orientation.
3. The episode finished when the child gave a clear sign of switching his/her attention away from the caregiver, e.g. averting gaze and stilling body, and did not respond again during the next five seconds.

Each sequence included the beginning and ending of the 'interaction' episode, with lengths varying between nine and thirty seconds. These 144 episodes were reviewed and a final selection of four 'interactions' per child was chosen that offered the best combination of visual clarity and variety of communicative behaviours.

The behaviours in the coding schedule are those the PMMH subjects and their caregivers were observed to use when they were reacting and responding to each other, but these physical and vocal behaviours are not necessarily communicative in themselves. The caregivers were attempting to establish and maintain communication throughout the recording session and their behaviours, therefore, can be reasonably considered 'communicative' in intent. However, one cannot assume that this was the case with the children: the purpose of their behaviours was often less clear. For example, the children sometimes displayed body movements which did not appear to be part of any communication. Therefore, it was important to select sections of recording sessions where there was considered to be no communication occurring for comparison with the episodes of 'interaction'. Therefore, four episodes of matching lengths, in which there was no communication, were selected, each containing behaviours which did not appear to relate to what the caregiver was doing or saying, to allow a comparison with similar behaviours observed during communication. Periods when a child did not display any behaviours were not included.

There were difficulties in selecting 'non-interaction' episodes for two children who responded to their caregivers throughout their recording sessions. The episodes identified as 'non-interaction' for

these children were therefore taken from the beginnings and endings of their sessions, when the caregivers were paying more attention to settling down or getting ready to finish, e.g. removing or putting on coats. Several other children showed no observable behaviours outwith periods of communication. In these cases, the selections for 'non-interaction' consisted of reactions of the child that were not followed up by further communicative expressions, e.g. the child smiled for a few seconds in response to being tickled, but did nothing further to extend the contact. In contrast, an 'interaction' might start with a smile and be followed by other behaviours such as vocalising, turning towards the caregiver and looking at her as she continued tickling and speaking to the child.

All selections were made by the researcher and a colleague who was experienced in the field of profound handicaps, and they viewed the videotapes together. Both had to be in complete agreement that each selection fulfilled the criteria for 'interaction' and 'non-interaction'.

The final selection of 'interaction' and 'non-interaction' episodes (4 per child of each) were edited onto a separate tape (one tape accommodated all edited selections). A millisecond digital electronic time counter, which recorded a frame advance every 40 milliseconds (25 frames/second), was added to every sequence and zeroed at the start of each sequence.

The episodes were transcribed using the *Interactive Behaviours* coding schedule in conjunction with an event analyser computer programme. Keyboard presses were allocated to each behaviour category for child and caregiver and a single behaviour was noted during each pass of the videotape. The programme logged behavioural events every 0.7 seconds (the lowest timing value available on the programme), providing a sequential analysis of the behaviours of caregiver and child for each 'interaction' sample and each segment of 'non-interaction'. Each pass of the same sequence began on the same frame of the tape. The approximate rate of coding was three hours per sequence.



Table 4.3 provides a simplified example of a coding sheet.

Table 4.3 Coding sheet

Seconds	Caregiver			Child		
	12 columns, 1 per category. Categories represented by A-L.			10 columns. Categories represented by M-V		
1			G		Q	
2	B		G		Q	
3	B	E	G	O	Q	
4		E	G	O	Q	V
5		E	G		Q	V
6	B	E	G			V

B=specific actions
 E=smile
 G=look

O=gestural actions
 Q=body movements
 V=vocal

The event analyser programme provided an overview of the time each child and adult spent in the various categories of behaviour and the sequencing of the behaviours during each selection. However, the timing value of 0.7 seconds per sample proved insufficient for finer grain analysis and, therefore, onset and offset times of behaviours were recorded manually using the electronic time counter. Onset and offset times were recorded from the first frame in which the action was observed and the last frame in which the action was visible.

3.2.2 Analyses

Descriptive analyses were used to reveal the structure of the communication observed between the children and their caregivers.

A total number of 2,892 observations were made of the behaviours of the 12 PMMH subjects and their caregivers. Table 4.4 shows the number and range of observations made within four main subdivisions.

Table 4.4 Summary of Observations	'Interaction'		'Non-communication'	
	Number	Range	Number	Range
Children	623	21-115	250	7-58
Caregivers	1203	25-159	816	44-120
Total	1826		1066	

The observations were categorised to allow a comparison of child and caregiver behaviours during periods of 'interaction' and 'non-interaction'. Comparisons were based on the percentage of time spent by the children and caregivers in each category during four episodes of 'interaction' and four episodes of 'non-interaction'. Percentages offered a more informative picture of how each child's time was allocated across the categories in these brief interactions than the frequency of behaviours. The duration of each occurrence of the behaviours was also of interest, and this too was compared between the two conditions.

Statview, a statistical package for the Apple Macintosh, was used for statistical analyses. Wilcoxon matched-pair signed-rank two tailed tests were used to detect any differences in the behaviours of the children and caregivers in the two conditions. The levels of significance reported in the text are those obtained from Statview. The summary of results presented in tables show results significant at .01 and .05 levels of probability.

Video Reviews with Mothers

The mothers each reviewed a complete, unedited recording. This material, therefore, did not coincide with all the episodes edited out for analyses and no direct comparisons were made. However, each mother was shown a recording that contained 'interactions' that were included in the main analyses, which afforded an insight into whether the mothers' subjective judgements were in general agreement with the systematic methods of analysis employed in the research.

3.3 Reliability

Two episodes per child (one 'interaction' and one 'non-interaction') were randomly selected and transcribed by a second independent rater, experienced in working with people with profound mental and multiple handicaps, who was given a two-day period of training in using an event analyser computer programme in conjunction with the *Interactive Behaviours* schedule.

Reliabilities were calculated using a formula for 'occurrence reliability' advised by Murphy (1987) for low frequency behaviours, which takes account of both errors of omission and commission. The formula used was:

$$R_{occ}\% = \frac{\text{Number of observations raters agreed behaviour occurred}}{\text{number of observations either rater scored behaviour}} \times 100$$

The reliability agreements for the 22 categories are listed in Table 4.5 Actual numbers of observations made by rater and researcher rather than percentage agreements are stated for behaviours which appeared infrequently in the reliability sample.

Onset/Offset: Reliability for onset/offset times was conducted using a rater who, in common with the rater in the previous reliability checks, was experienced in working with people with profound handicaps. The researcher showed the rater 36 examples of behaviours (3 per child). The rater was asked to note onset and offset times for each example using the criteria described in the above paragraph. The rater and researcher had to agree on 'onset' and 'offset' within four frames (160 milliseconds). On this basis, agreement was found in 30 of the 36 examples. There was complete agreement on all examples within ten frames (400 milliseconds).

Table 4.5 Reliability Agreements for 'Interactive Behaviours' Schedule

Caregiver		Child	
Category	% Agree	Category	% Agree
Hand/Body	80	Hand/Body	88
Specific Actions	99	Gest. Action	87
Monitor	98	Orient	82
Moulding	78	Moulding	73
Smile	82	Body Movts.	89
Facial Express.	[*3/3]	Body Stir	75
Look	91	Smile	83
Facial Closeness	89	Fac. Movts.	84
Body Games	89	Look	90
Toy	77	Vocal	94
Sing	[*2/2]		
Vocal	92		

*The no of agreed events observed by researcher and rater - Res/Rater

CHAPTER 5: STUDY 1

RESULTS

1. INTERACTIVE BEHAVIOURS

All ten categories of child behaviours were present in interaction episodes (I). Five of those categories were also exhibited in non-interaction (**non-I**) episodes by two or more children, four were exhibited by a single child, and one category of behaviours ('gestural action') was absent. All twelve categories of caregiver behaviours were observed in I, with eleven also exhibited by at least two caregivers in **non-I**, while one behaviour, 'facial expression' was absent. It was possible, therefore, to make some form of comparison between all but two categories of behaviour in I and **non-I**, and to explore possible differences between the same behaviours in the two different types of episode.

1.1 Percentage and Duration of Behaviours

1.1.1 PMMH Subjects

The mean percentage of time the PMMH subjects spent in each category of behaviour during I and **non-I** episodes was calculated. The percentages were greater in I for behaviours which suggested awareness and acknowledgment of the caregiver's interventions and Wilcoxon matched-pair signed-rank tests showed these higher percentages to be significant in four categories: 'orient' ($p=.0425$), 'smiles' ($p=.0022$), 'look' ($p=.0173$) and 'vocal' ($p=.0044$). A higher percentage of 'body movement' was found in **non-I** and this too proved to be significant ($p=.0469$). Table 5.1 summarises the results for each category in both I and **non-I**.

Table 5.1 Mean Percent of Time Spent by PMMH Children in Behaviour Categories during Interaction and Non-Interaction Episodes

Category	Episode	Number of Subjects	Mean	S.D.	Min.	Max.
H/B	I	2	3.6	8.4	0	21.5
	<i>non-I</i>	1	0	0	0	0
Gest. Action	I	6	4.9	9.4	0	25.2
	<i>non-I</i>	0	0	0	0	0
Orient	I	7	11.3*	18.8	0	48
	<i>non-I</i>	1	0	0	0	0
Moulding	I	4	6.9	12.4	0	34.2
	<i>non-I</i>	1	0	0	0	0
Body Movt.	I	7	9.5	14.2	0	47.0
	<i>non-I</i>	9	20.7*	18.3	0	49
Body Stir	I	5	4.7	7.5	0	24.5
	<i>non-I</i>	7	5.8	8.8	0	22.5
Smile	I	12	38.5**	23.2	2.2	72.0
	<i>non-I</i>	1	0	0	0	0
Facial	I	8	12.4	14.6	0	40.0
	<i>non-I</i>	8	9.4	10.4	0	26.2
Look	I	°8	51.6*	27.1	10.8	91.5
	<i>non-I</i>	8	13.0	14.1	0.2	39.2
Vocal	I	11	16.0**	11.0	0	37.2
	<i>non-I</i>	6	3.2	4.2	0	11

* $p < .05$

** $p < .01$

°Calculations for 'look' exclude the 4 blind subjects

The mean durations of the behaviours were also computed, to determine whether there was any pattern of increase or decrease between I and *non-I*. No such trends emerged, but Wilcoxon tests did show three behaviours to have significantly longer durations in I: 'smile' ($p = .0022$), 'look' ($p = .0173$) and vocal ($p = .0408$). Only one subject was observed to use 'smile' in *non-I*, and a significant difference between durations is, therefore, unsurprising. However, an equal number of subjects used 'look' in both I and *non-I* and more than half used 'vocal' in both,

suggesting that the longer durations in these two behaviours were influenced by the child’s engagement with the caregiver. Table 5.2 summarises the results.

Table 5.2 Mean Duration (in secs) of Child Behaviours during Interaction and Non-Interaction Episodes

Category	Episode	Number of Subjects	Mean	S.D.	Min.	Max.
H/B	I	2	1.1	3.1	0	10.6
	non-I	1	0	0	0	0
Gest. Action	I	6	1.1	1.6	0	4.4
	non-I	0	0	0	0	0
Orient	I	7	2.5	4.5	0	14.5
	non-I	1	0	0	0	0
Moulding	I	4	3.4	7.2	0	19.2
	non-I	1	0	0	0	0
Body Movt.	I	7	1.4	2	0	6.9
	non-I	9	4.9	6.2	0	2.6
Body Stir	I	5	0.9	1.6	0	5.4
	non-I	7	0.8	0.9	0	3.2
Smile	I	12	7.3**	5.2	0.9	18.2
	non-I	1	0	0	0	0
Facial	I	8	1.8	2.8	0	8.7
	non-I	8	2.6	3.9	0	13.6
Look	I	°8	12.3*	12.8	2	27.8
	non-I	8	3.5	4.9	0.3	15
Vocal	I	11	1.5*	0.7	0	2.7
	non-I	6	0.7	1.1	0	3.7

*p<.05

**p<.01

°Calculations for ‘look’ exclude the 4 blind subjects

Descriptive Comments

Hand/Body: Two children used hand/body contact in the I episodes, but only one was observed to use this behaviour in both I and non-I, with most of the latter occurring during one non-I episode (95% of the episode). In contrast, the percentages were more evenly distributed during I episodes. This child communicated throughout his recording sessions and it was difficult to obtain examples of non-I. Some non-I episodes were selected from the endings of sessions when the caregiver was making preparations to leave the room, her attention focused away from the child. It is possible that, in the episode in which 'hand/body contact' was observed for 95% of the time, this contact was, in fact, 'communicative' and that the child was attempting to catch the caregiver's attention, persisting for longer than usual when she did not give her usual response.

Gestural Action: This action describes a physical form of request directed towards another person. Such actions were used by six children in I, but none in non-I. Each child clearly demonstrated his or her wishes with specific movements and postures which were immediately understood by the caregivers. These actions were not confined to the more physically able children: some children who used these personalised 'gestures' had extremely restricted mobility. Two of the children were also blind, supporting the suggestion that 'gestural actions' are not imitative, but evolve from idiosyncratic movements which gain meaning through interpersonal contact.

Orient: Most actions in this category took the form of head turning or tilting the body towards the adult. Seven children were observed to orient towards the caregiver during I, with one child also orienting during non-I: 'Orient' was not a prominent feature of this latter child's communication and it is possible that turning his body towards the caregiver did not necessarily signify his interest in her. Three of the four blind children spent a large percentage of the time (up to 85%) 'orienting' towards their caregivers. The fourth child rarely 'oriented', but did spend over twenty percent of the time in I using 'gestural actions' and 'hand/body contact', suggesting that his lack of 'orienting' arose from his

personal style of communicating, and not from a lack of interest in his caregiver.

Moulding: Four children were seen to use this behaviour during I, but only one child used 'moulding' in non-I. This child, who was blind, spent just over one third of the time in this form of close body contact in both I and non-I. He nestled into the shape provided by the caregiver's posture, adjusting his position with the caregiver's changes in body shifts to maintain the contact. During non-I when the child's attention was switched away from the caregiver, he continued to show these adjustments. It is difficult to interpret the meaning of the child's behaviour in these instances and he may simply have been seeking a comfortable resting position, treating the adult rather like a 'comfortable chair'. Another child who had profound visual and hearing impairments spent around 25% of the time in I moulding and adjusting to the caregiver's body shape. The caregiver reported that she used these body cues to gain information about the child's response and participation.

Body Movements: The significantly higher percentage of body movement observed during non-I is interesting. It can be very difficult to decipher the meaning and intention of the body movements of children with profound mental and multiple handicaps and it is difficult to distinguish movements which are part of the communication from those which are non-communicative. Many children with profound multiple handicaps have poor control of their movements, some of which may be involuntary, e.g. the hand stereotypies of girls with Rett syndrome, adding further difficulties when judging which movements might be 'communicative'.

The same limb movements which accompanied smiling, turning towards the caregiver and vocalising might also be seen when the child is paying no attention to the adult. In fact, these accompanying behaviours can help to distinguish 'communicative' body movements from 'non-communicative' ones: during non-I the movements often occurred in isolated phrases or with accompanying vocalisations which did not appear to be directed at the adult, and were unvaried and

repetitive. There was little difference in durations. However, two children, Julie and Mark, did have greatly increased durations. During these longer bouts the children's movements were unvaried in nature and appeared unrelated to anything the adult was doing, giving the appearance of 'cutting across' a conversation.

The pattern reflected in the group results was not seen in every case, as shown in Table 5.3, but a majority of children did show an increased percentage during non-I, with three of these children displaying no body movements at all during I.

Table 5.3 Mean Percents and Durations of Body Movements during Interaction and Non-Interaction.

Subject	Percent		Duration	
	I	non-I	I	non-I
David	0	7.2	0	3.9
Colin	0	31.2	0	2.3
Steven	18.8	43.0	1.3	4.6
Cathy	0	1.8	0	0.5
Susan	0	0	0	0
Julie	3	49	1.6	13.8
Mark	17.8	23.0	2.4	20.0
John	4.0	31.8	0.6	8.1
Greig	47.0	23.2	6.9	3.3
Sheila	0	0	0	0
Linda	4.2	0	0.9	0
Jane	19.5	38.2	3.1	2.8

The two children, Susan and Sheila, who displayed no body movements in either I or non-I had little independently controlled movement. While this may explain their lack of movement, it is worth noting that two other children with similar restrictions, Colin and Julie, did exhibit body movements during I and non-I, with a greatly increased percentage during non-I. One child, David, who had very severe physical impairments also displayed body movements during non-I, but none during I. Therefore, there were clear individual differences in the amount of movement the children displayed which did not depend

solely on their physical capacities. Some children made full use of their limited options, while other more physically able children were less active.

The movements need to be viewed in context to gain an understanding of their possible communicative significance. If a child is seen to consistently begin his phrases of response with a burst of body movements it is probable that these particular movements form part of his pattern of response. It is also possible for a child's body movements to have interpersonal significance when he or she is not engaged in interactions, e.g. signifying a child's discomfort during moments of intense input from the caregiver when he does not want to become involved in interpersonal contact.

Body movements clearly play a role in some children's styles of response, even when their range of movement is limited and quality of performance is poor.

Body Stir: This behaviour was observed in almost equal amounts in both I and non-I. Although the category already describes minuscule body behaviours, sub-dividing these behaviours into even greater detail might prove more discriminatory. For example, 'body stirring' which involves the body as one unit, e.g. a slight raising and arching of the upper body as the child vocalises while looking at the caregiver seems qualitatively different from 'body stirring' involving tiny movements of the limbs and hands, such as finger movements. It might be more appropriate to include these events within another category, extending the definition of 'orient' to include the sorts of events described by the first example, and incorporating the tiny body shifts and finger movements in 'body movements'. However, the behaviours described by 'body stirring' do appear to possess a distinct quality and it might be more helpful to refine the definition of the category so that these events can be captured more effectively.

Smile: All the children were observed to smile during I, showing a clear discrimination between I and non-I. Only one child smiled during both, but with a greatly reduced percentage in non-I. Her smiling in non-I was

not directed at the adult, but occurred when she was shuffling round the room some distance from the adult and preoccupied with her own actions.

Facial: The facial movements and expressions of children with profound mental and multiple handicaps are not always easy to decipher. Automatic mouthing movements and facial grimaces can appear meaningful while communicative expressions can be mistaken for grimaces. Personal knowledge is helpful in making sense of the child's expressions, e.g. seeing that a child consistently widens and narrows his mouth when responding communicatively, but rarely when unresponsive or alone. Six children, in particular, showed a very clear discrimination between the two types of episodes, three using a greater amount in I and three in non-I, as displayed in Table 5.4.

Table 5.4 Mean Percentage and Duration of 'Facial Movements'

Subject	I %	non-I %	I (secs)	non-I (secs)
David	38	9	8.7	3.3
Steven	24	1	2.9	0.3
Sheila	40	21	5.8	4.7
Susan	0	18	0	3.4
Julie	11	26	0.3	13.6
Linda	6	22	0.3	2.9

It is possible that the higher incidence of these movements in non-I for Susan, Julie and Linda reflects habitual patterns, non-communicative patterns which were reduced while their attention was engaged and they were actively responding to the caregiver. The mean duration of Julie's facial movements was 13.6 seconds in non-I compared to 0.3 in I, supporting the qualitative differences observed between the two types of episode: her facial movements in I appeared to be part of her typically brief forms of response to her caregiver's interventions. David and Steven consistently showed very distinct types of facial actions when responding to their caregivers, that were not apparent during non-I.

Look: The sighted children all looked at their caregivers in both I and non-I, though for a shorter duration in non-I. In the latter, some children appeared to look 'through' the caregiver with their attention focused elsewhere. Others looked directly with an unwavering stare, but with no other reaction towards the adult. In contrast, the looks during I were accompanied by other communicative reactions.

Vocal: Eleven children vocalised during I and six during non-I. They were found to vocalise for a greater percentage of the time during I, with longer durations. However, there were individual differences: some children vocalised only rarely with quiet, brief sounds, while others were far more vocal. In common with body movements, the vocalisations in non-I appeared more repetitious in a similar way to 'body movements', and did not seem to be directed towards the caregiver.

Children smiled, looked and vocalised for a greater percentage of the time of the time during interactions than they did when their attention was not directed towards the caregiver - this difference being especially marked in smiling and looking. All but one of the children who oriented only did so during interactions. These findings are helpful in confirming that the usual features of non-verbal communication, such as smiling and looking, can play a prominent role in the communication of this group of children. However, not all the PMMH subjects responded through these more usual channels of communication, and Section 2 (Individual Styles) explores further the children's individual styles of communicating.

1.1.2 Caregivers

The mean percentages of time spent by caregivers in the various categories of behaviour were also calculated, along with the mean durations of the behaviours. Table 5.5 shows that the caregivers 'monitored' the children's actions, smiled, looked, and held their faces very close to the children for a higher percentage of time during I. Wilcoxon tests showed these differences in behaviour to be significant: 'monitor' ($p=.028$); 'smile' ($p=.0033$); and 'look' ($p=.0497$). However, the

differences observed between I and non-I were not all in the same direction: caregivers used play with toys for a significantly higher percentage of time in non-I, ($p=.0414$). In all other categories there was little difference observed between the two types of episode.

Table 5.5 Mean Percent of Time Caregivers Spent in Behaviour Categories during Interaction and Non-Interaction

Category	Episode	Number of Subjects	Mean	S.D.	Min.	Max.
H/B	I	6	3.1	4.7	0	15
	non-I	4	4.0	7.0	0	21.5
Spec. Act.	I	12	28.9	23.7	3.8	75.5
	non-I	12	28.9	17.8	5.0	66.5
Monitor	I	6	10.6*	15.3	0	49.5
	non-I	6	2.1	3.8	0	2.8
Moulding	I	6	29.0	31.2	0	96.0
	non-I	8	24	30.9	0	99.3
Smile	I	11	26.6**	19.5	0	58.0
	non-I	7	2.4	3.5	0	10.8
Fac Ex.	I	2	.8	2.3	0	8
	non-I	0	0	0	0	0
Look	I	12	88.8*	11.2	65.8	100
	non-I	12	80.7	14.7	57.8	99.8
Fac. Close	I	11	52.8	29.6	0	100
	non-I	10	27.6	35.3	0	100
B. G.	I	9	12.1	13.1	0	37.2
	non-I	7	11.0	12.7	0	40.8
Toy	I	6	7.0	12.2	0	37.2
	non-I	9	18.7*	19.1	0	23.5
Sing	I	3	4.6	9.6	0	31.2
	non-I	2	2.2	6.8	0	23.5
Vocal	I	12	42.4	13.8	14.5	63.5
	non-I	12	37.6	16	5.8	56.2

* $p<.05$

** $p<.01$

The mean durations are displayed in Table 5.6. These show little difference between I and non-I. However, Wilcoxon tests revealed a significantly longer duration for 'smile' ($p=.0033$) during I and for 'toy' in non-I, ($p=.0166$).

Table 5.6 Mean Duration (in secs) of Caregiver Behaviours in Interaction and Non-Interaction

Category	Episode	Number of Subjects	Mean	S.D.	Min.	Max.
H/B	I	6	1.5	2.5	0	8.4
	non-I	4	1.1	2.6	0	8.9
Spec. Act.	I	12	3.7	2.8	0.4	9.8
	non-I	12	5.7	5.5	0.4	16.1
Monitor	I	6	1.0	1.4	0	3.9
	non-I	6	0.3	0.4	0	1
Moulding	I	6	11.7	12.5	0	28.5
	non-I	8	7.5	10.3	0	25.7
Smile	I	11	3.5**	2.3	0	7.4
	non-I	7	0.6	0.6	0	1.8
Fac Ex.	I	2	0.1	0.4	0	1.3
	non-I	0	0	0	0	0
Look	I	12	18.6	8.8	4.6	29.7
	non-I	12	17.1	11.1	4.7	29.1
Fac. Close	I	11	12.8	11.6	0	28.3
	non-I	10	8.0	11.0	0	29.2
B. G.	I	9	3.1	4.1	0	13.7
	non-I	7	2.2	4.6	0	16.6
Toy	I	6	1.2	2.0	0	6.4
	non-I	9	4.3*	4.0	0	13.6
Sing	I	3	1.8	4.3	0	14.4
	non-I	2	0.3	0.6	0	1.4
Vocal	I	12	1.7	0.7	1.1	3.5
	non-I	12	1.9	0.9	0.9	3.4

* $p<.05$

** $p<.01$

Descriptive Comments

Hand/Body: This form of passive contact, usually placing a hand on the child while speaking, did not play a prominent part in the caregivers' behaviours. It was not used to elicit responses, appearing to be used more as a way of conveying interpersonal warmth.

Specific Actions: The active forms of contact movements, such as patting, were used by all twelve caregivers in both I and non-I. During I caregivers appeared to use the actions to hold the child's attention and maintain the liveliness of the interaction, while in non-I they were used in an attempt to attract the interest of an unresponsive child. Most of these actions took the form of 'action cycles' which are presented in detail in Chapter 8.

Monitor: 'Monitor' describes an active behaviour, in which the caregiver shadows the child's body movements and shifts of posture with her/his own body movements and changes in posture. In both I and non-I these tracking movements were brief and appeared to help the caregiver make the necessary adjustments to keep the best view of the child, or to follow the child's line of attention. The significantly higher percentage in I may have resulted from the children's higher amount of activity during interactions, i.e. the children were producing more behaviours to be tracked.

Moulding: This category featured prominently in some caregivers repertoires, while it was used little by others. It was observed more often with children who needed a lot of physical support, although one caregiver showed a high percentage of 'moulding' with a child who needed little support, but who sought this form of contact. This was not simply passive cuddling: the caregiver encompassed the child's body shape, whatever his or her position, and was not always in body contact, with both body shapes forming a 'sculpture'. One caregiver reported this to be an important element in gauging her child's communicative involvement, based on the way she moulded into the caregiver's body posture when she was holding her. She felt her own 'moulding' round the child's body shape helped the child to relax and that she did not respond to people so well who did not 'envelope' her in this way.

Smile: All but one caregiver smiled during I and seven during non-I. In the latter they were smiling their encouragement, trying to coax a response, whereas in I the smiling was in response to the child's smile or in reaction to his or her responses.

Facial Expressions: All caregivers maintained pleasant facial expressions. There were changes in expression but the detailed analysis necessary to describe these changes is outside the scope of this study. Two caregivers did use exaggerated expressions during play. In all instances the children laughed or smiled broadly in response, these exaggerations obviously being a part of each pair's repertoire of interpersonal play.

Look: The caregivers kept a close watch on the child for the majority of the time in both I and non-I, spending a far higher percentage of time looking at the child than in other categories of behaviour. The duration of the 'looks' was also longer than that of any other behaviour in both I and non-I. There were variations observed between the individual caregivers, some watching the child throughout the episode, but even the lowest recorded percentages were 66% in I and 58% in non-I.

Facial Closeness: This was also a strong feature of the caregivers behaviours, but their pattern of use was mixed. Some held their faces very close during I with a decreased percentage in non-I, while others showed the reverse pattern, as shown in Table 5.7. The child's name is used to represent each caregiver.

Apart from the one caregiver who was not observed to use 'facial closeness' the behaviour appeared to have an interpersonal role in both I and non-I, occurring both during interactive exchanges and during attempts to prompt a response. When the video records were examined the low percentages were seen in caregivers who usually pulled back from the child when he or she was unresponsive, continuing to watch and speak to the child, but without physical intervention.

Table 5.7. Mean Percentage of Facial Closeness during Interaction and non-Interaction

Subject	I	non-I
David	60.2	87.5
Colin	0	0
Steven	63.0	2.0
Cathy	86.5	7.0
Susan	100	0
Julie	32.5	54.5
Mark	39.0	25.2
John	58.5	37.0
Greig	26.5	3.8
Sheila	69.5	9.8
Linda	78.0	100
Jane	20.0	4.2

Body Games: These described games improvised by the caregiver that were used during both I and non-I to maintain or to prompt responses, showing a similar purpose to 'specific actions'.

Games with Toys: These games were typically brief: caregivers would often use a variety of different actions in succession, such as squeaking a toy, walking it up the child's arm, bouncing it on his knee, pausing for a time between each to watch the child's response. Six caregivers used toys in this way during I, with the number increasing to nine in non-I. Some of the children had favourite toys and their caregivers were seen presenting these to the child when unresponsive, in an attempt to capture his or her attention.

It was clear from watching the recordings that caregivers sometimes interrupted the flow of the interaction by turning away to pick up a toy and then encouraging the child to react to it. Children tended to switch their attention away from the caregiver when interrupted in this way. One mother remarked on such an event during the video reviews,

observing that her child, who had previously been responding well, had lost interest when she (the mother) introduced toys. Watching the video replay, she could see that the child preferred direct contact with her. Therefore it is possible that sometimes children could be *discouraged* rather than *encouraged* by the persistent use of toys.

Sing: Only a small number of caregivers sang to the children during episodes. On all occasions the songs and the accompanying actions were well-known to the children, and when they responded they interjected their own sounds into the caregiver's singing and showed anticipation through their movements and postures of the next part of the song.

Vocal: All of the caregivers spoke to the children in both I and non-I, commenting on what the child was doing, referring to events in the child's day, commenting on how he or she might be feeling and on what the child might be thinking. This was also helpful in gaining an idea of the adult's evaluation of the child's responses and participation.

The caregivers used a variety of tactics to persuade the child to respond and to maintain his or her involvement once engaged, and they used many of these in both I and non-I. However, the caregivers did not have identical patterns of distribution across the categories of behaviour and these are presented and discussed in Section 2.

1.2 Video Reviews by Mothers

The parents did not select for comment any parts of the session from which non-communication episodes had been edited. The behaviours that determined the parents' selections were similar to those in the main analysis. All the behaviours can be accommodated in the Interactive Behaviours schedule, indicating general agreement between the mothers' observations and the criteria used for the main analysis.

The five mothers were all able to make confident judgements of when they felt their child to be aware and responding and could all pinpoint the behaviours that enabled them to make their selections. The

mothers' accounts, based on their intimate knowledge of their child, provide an insight into the detailed information that parents have of their own child. Sometimes based on obscure reactions and behaviours, these kinds of observations offer an important source of information to all who work with the child, contributing to a repertoire of communication whose meanings are shared by both partners. The observations are summarised below:

Julie uses facial expressions, movements of her nostrils, tiny shifts in posture and tiny body movements to communicate. She uses eye movements and head movements to orient to sounds. When she opens her eyes wide it means she is very aware. She likes close body contact and responds well if people 'wrap their bodies' round her when holding her. She makes soft sounds when happy and contented and loud sounds when not pleased or in an excited mood.

David communicates very readily with facial expressions, smiles and sounds, each with their own meaning. He has different ways of looking, e.g. 'petted look', 'serious look', 'anticipating look', 'dirty look'. He stirs his body and moves his face when responding and trying to communicate something. When he is upset he cries, moans and whimpers. He likes being with people and likes them to speak directly to him rather than trying to interest him in toys.

Cathy communicates through different sounds and body movements, squeezing her body with her arms, and smiling and looking at people. She cries when upset or in pain. She will lift her head in anticipation of expected events and will lift her head and hold her arms in a certain way when she wants a cuddle. She follows what her mother is doing with her eyes. People have to be very close to her if they want her to respond.

Susan shows that she is responding well when she opens her mouth very wide and usually makes noises from the back of her throat. She makes different noises when happy, sad or fed-up and uses noises more than facial expressions when upset. She puts her tongue out when she is thirsty. In general, she communicates through facial expressions, smiling, tiny body movements, "looking" towards people, and holding her head very still. She prefers people to toys.

Colin communicates by smiling, looking at people and vocalising. He uses body movements, moving his legs more than his arms, and dances when he is very excited and involved, but needs time to 'get this going'. People have to keep up the stimulation if they want him to respond. He shows different reactions to different people. When someone comes into the room he always looks at them and seems to expect a response from them, quickly losing interest if there is no response.

The mothers' video reviews are discussed further in the final discussion in Chapter 10.

2. INDIVIDUAL STYLES

All twelve children showed a consistent individual pattern of distribution across the four 'interaction' episodes, one that was different from any pattern seen in their 'non-interaction' episodes. Although these patterns were possibly shaped to some extent by the nature of their physical and sensory disabilities, these cannot account for all of the differences observed. As the observations in Section 1.1.1 illustrated, possessing the physical capacity to communicate in a certain way does not guarantee its occurrence, e.g. a sighted child might rarely give eye contact.

No child showed the same pattern of distribution in both I and non-I, as Figures 5.1a - 5.12b show overleaf. This suggests that the children have personal styles of communication based on cohesive forms of response which can be identified as different from their pattern of behaviours when they are not involved in interpersonal contact.

When the caregivers patterns of distribution were compared between I and non-I there were no marked variations between the two types of episode, but differences were seen between the different caregivers (see Figures 5.13a - 5.24b). Only 'looking' showed a consistent pattern across the caregivers, indicative of the close watch all caregivers kept on the child.

The adults concentrated on the approaches they knew had the best chance of success, based on their experience of many interpersonal exchanges with the child. These predictions would not be possible if the child's responses were haphazard and indiscriminate. The children's consistent communicative style appears to shape and influence the caregiver's style, producing a distinctive appearance or 'hallmark' to each child-caregiver pair.

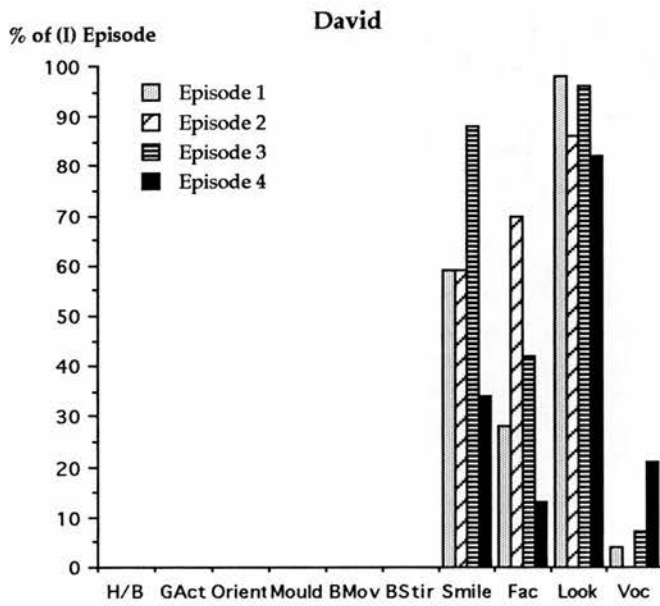


Fig. 5.1a Behaviour Categories

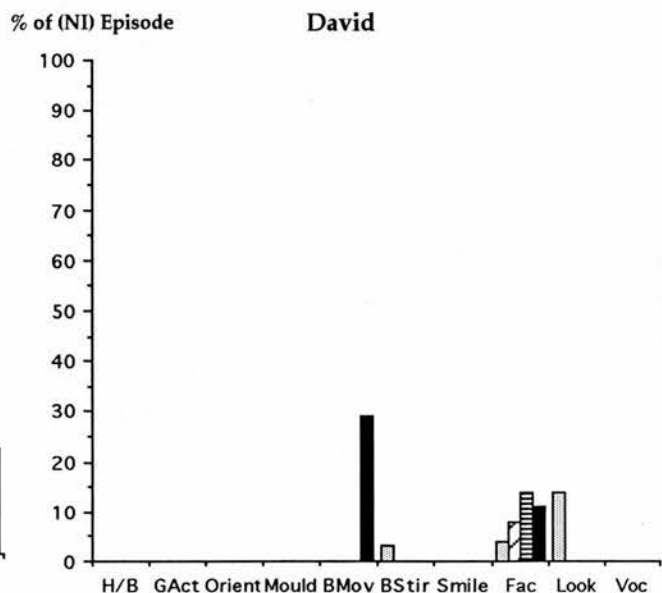


Fig. 5.1b

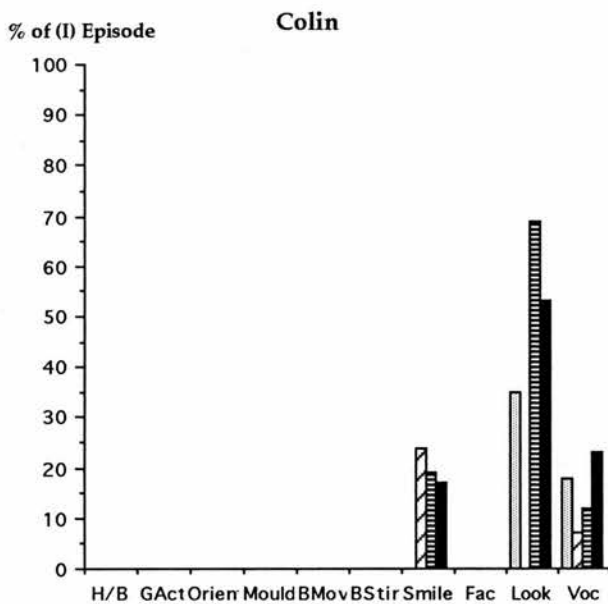


Fig. 5.2a

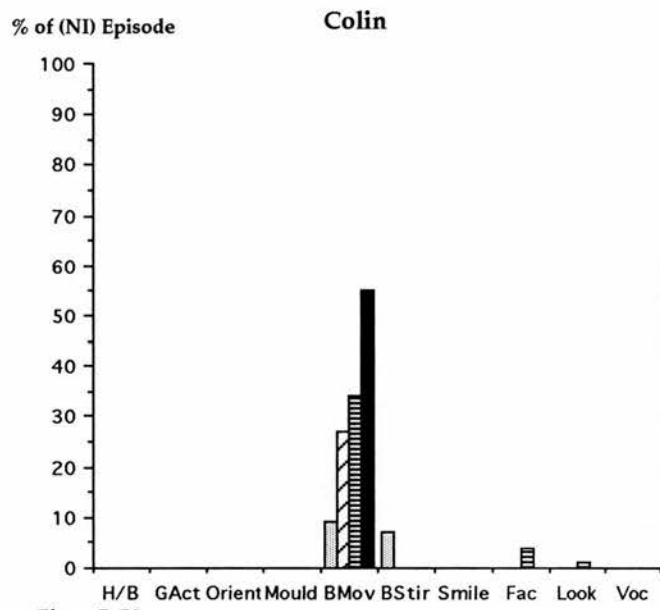


Fig. 5.2b

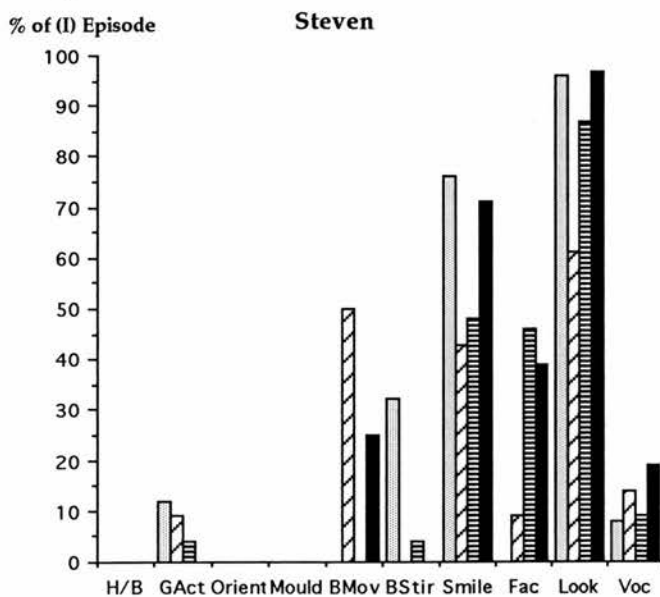


Fig. 5.3a

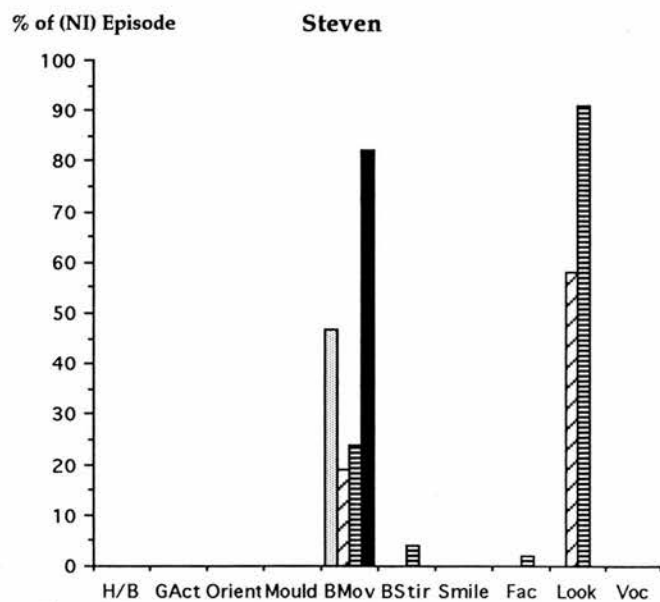
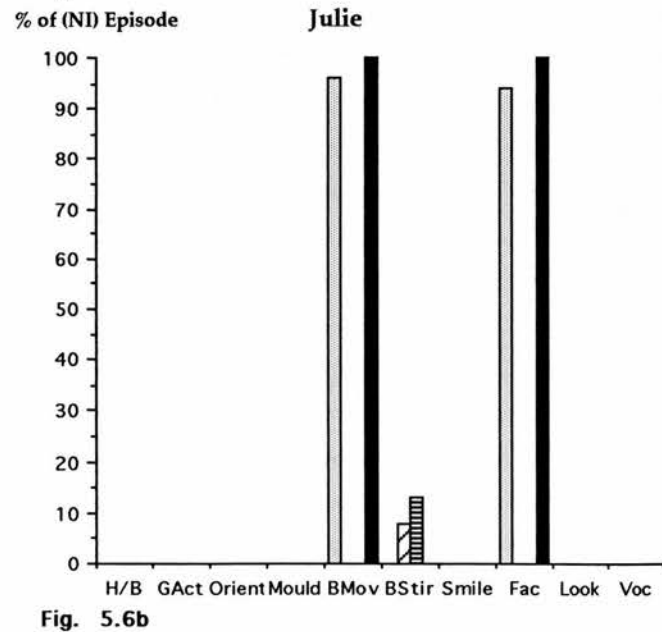
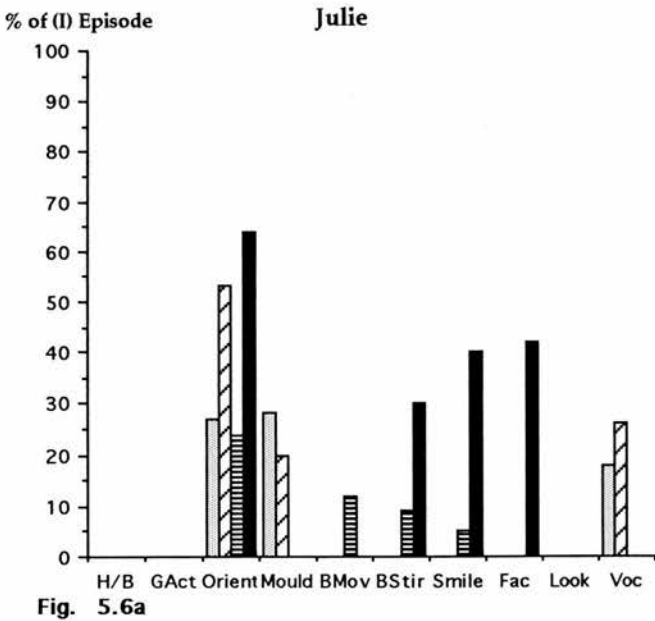
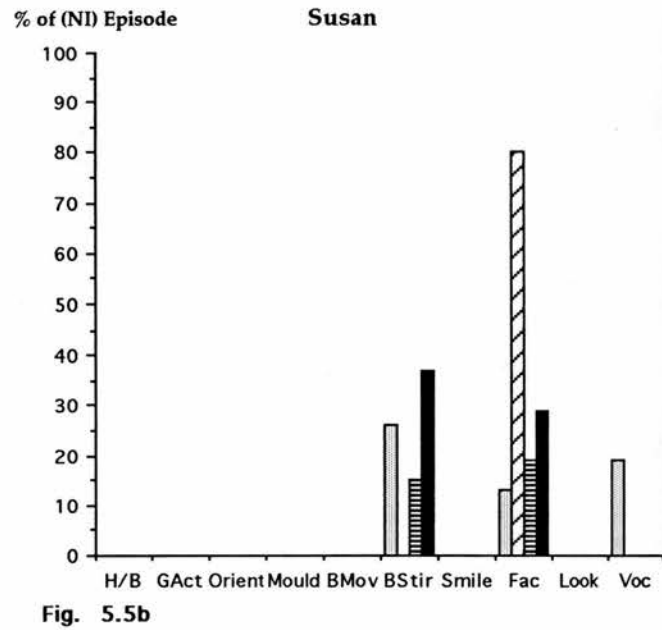
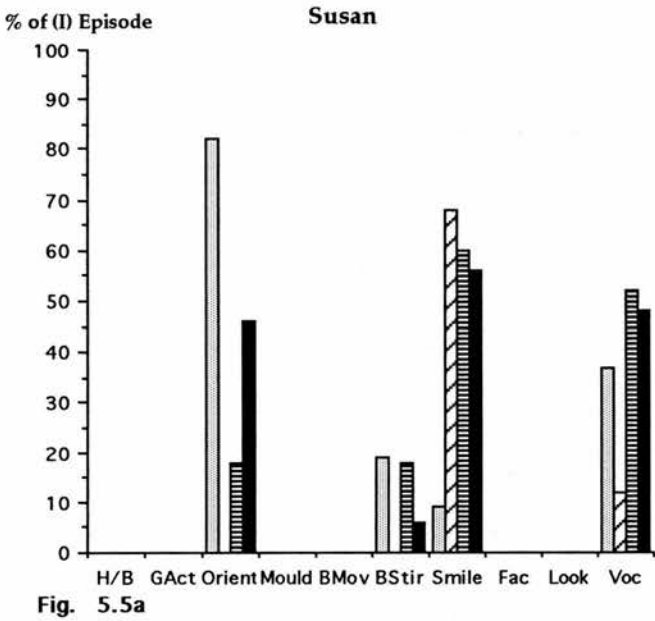
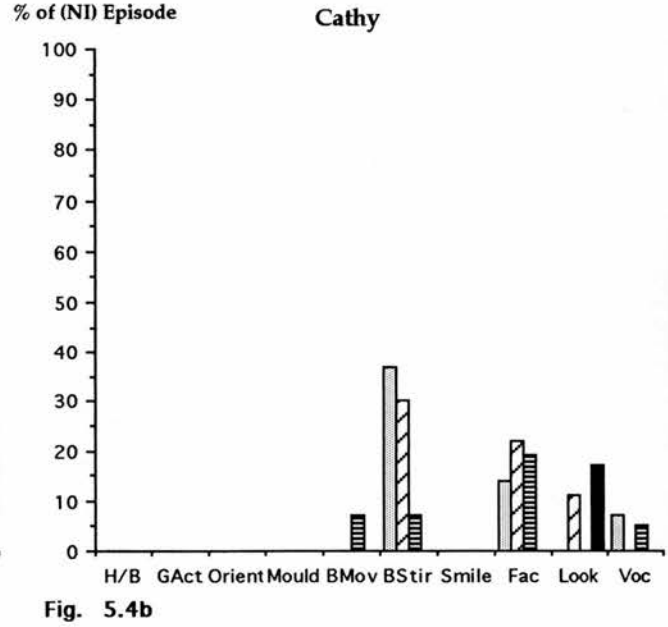
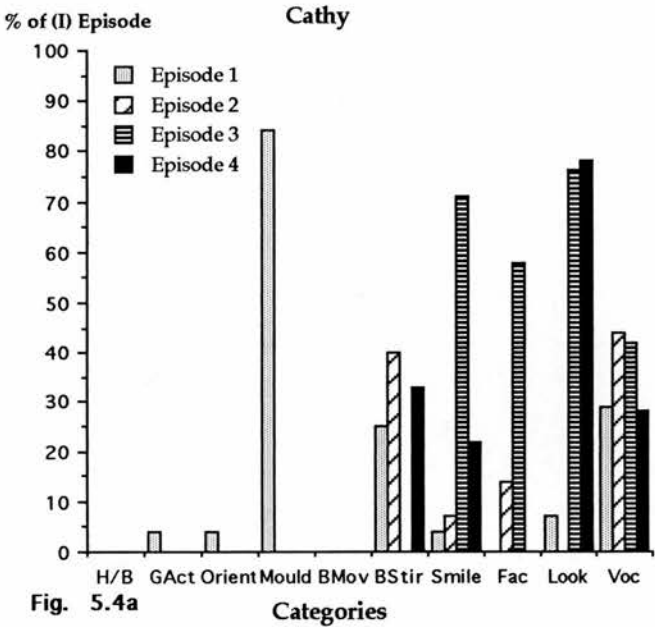
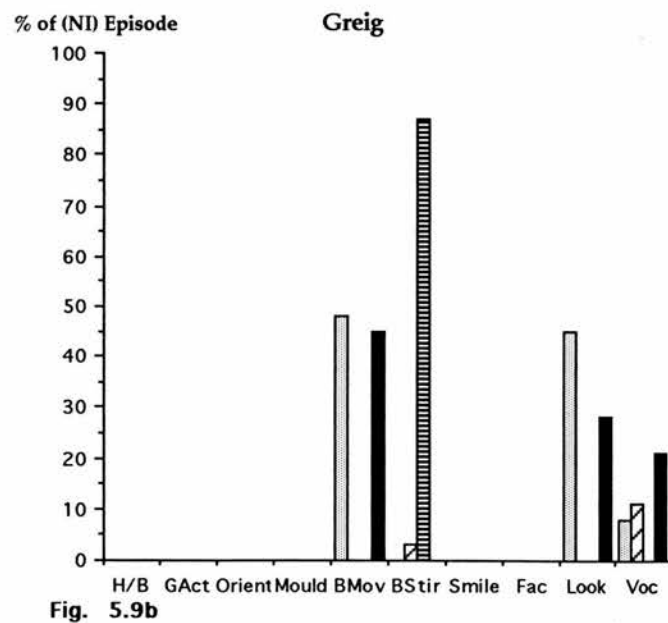
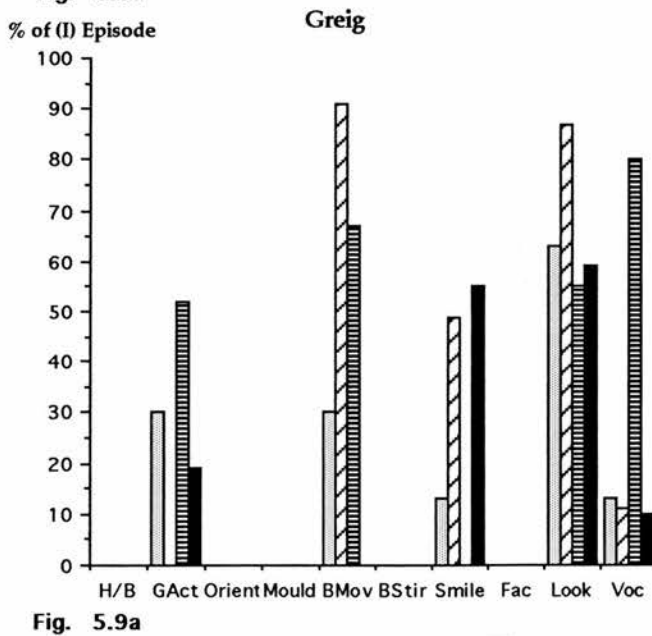
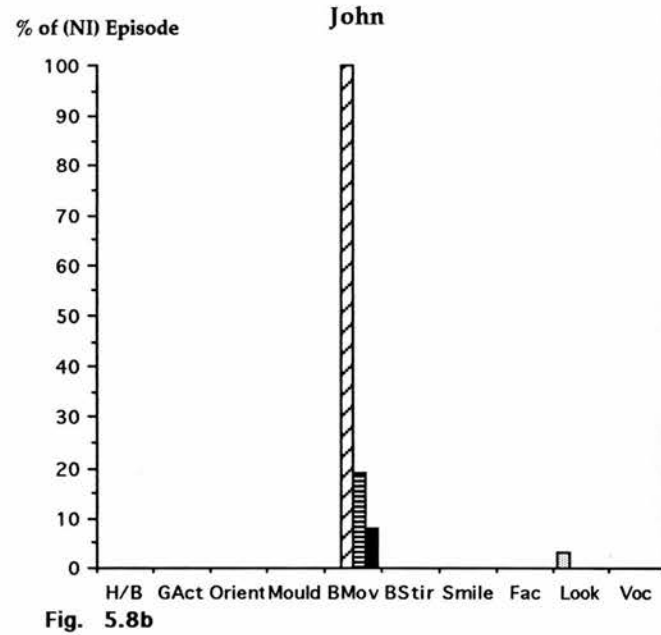
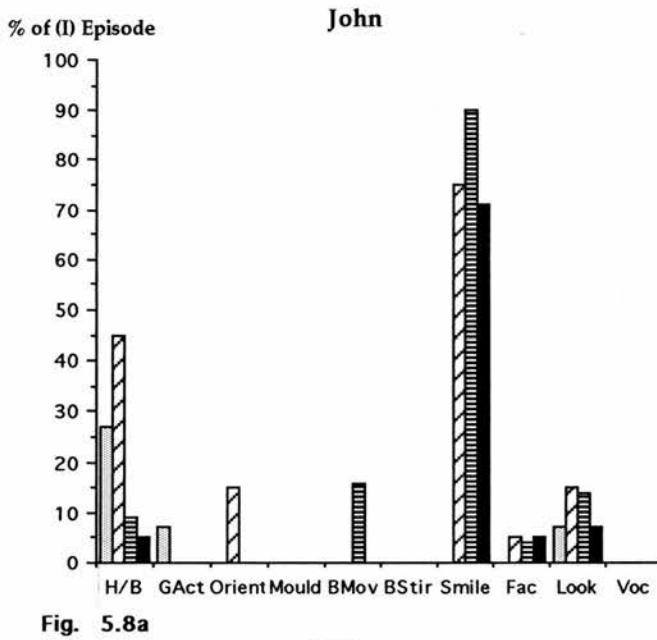
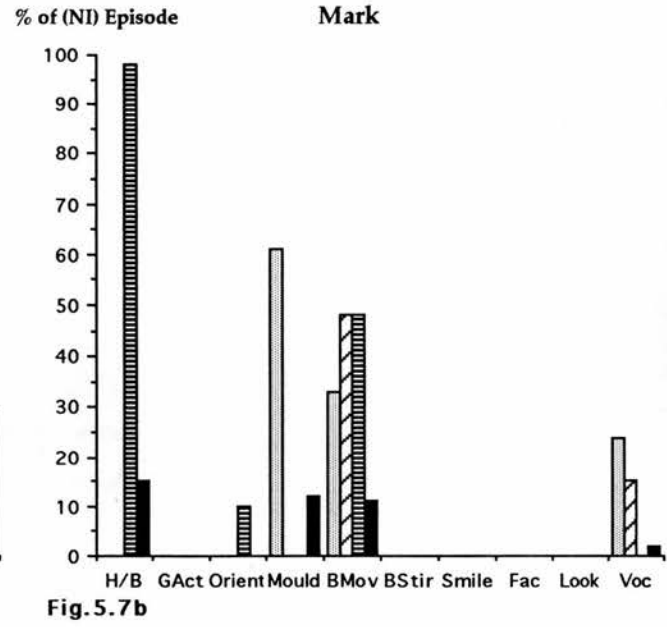
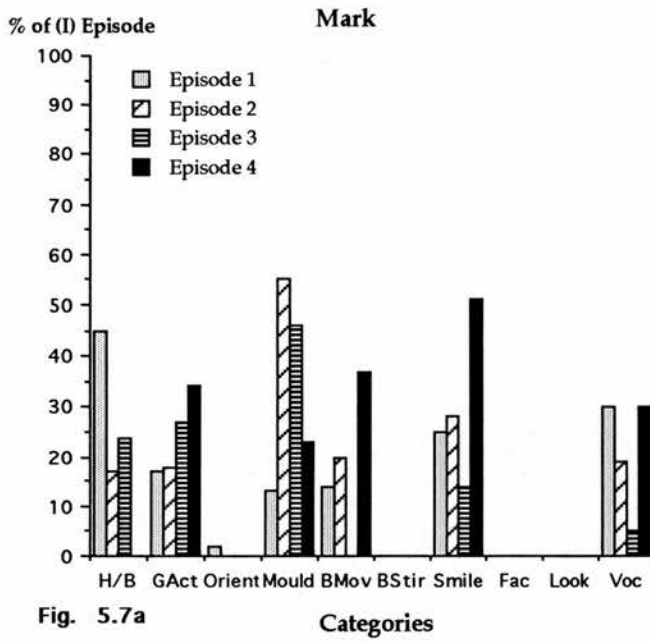
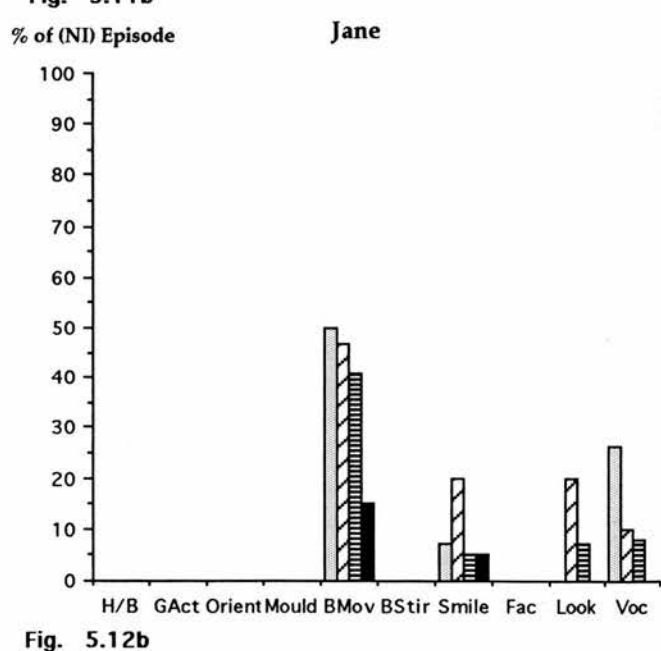
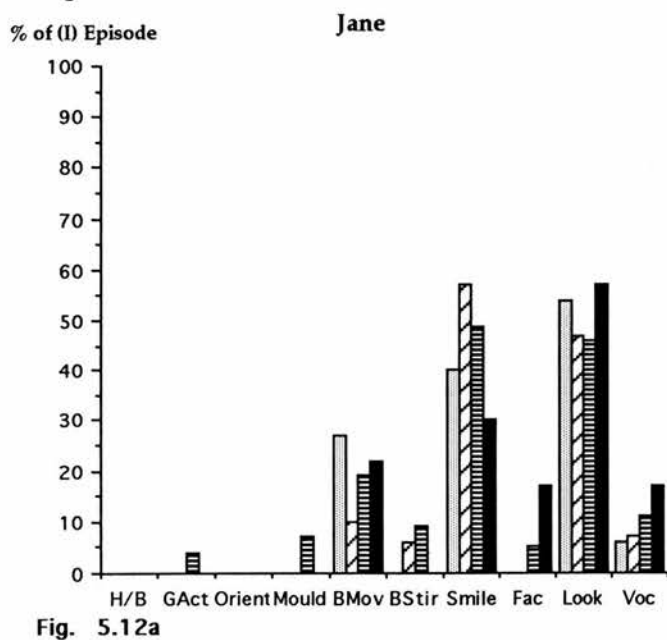
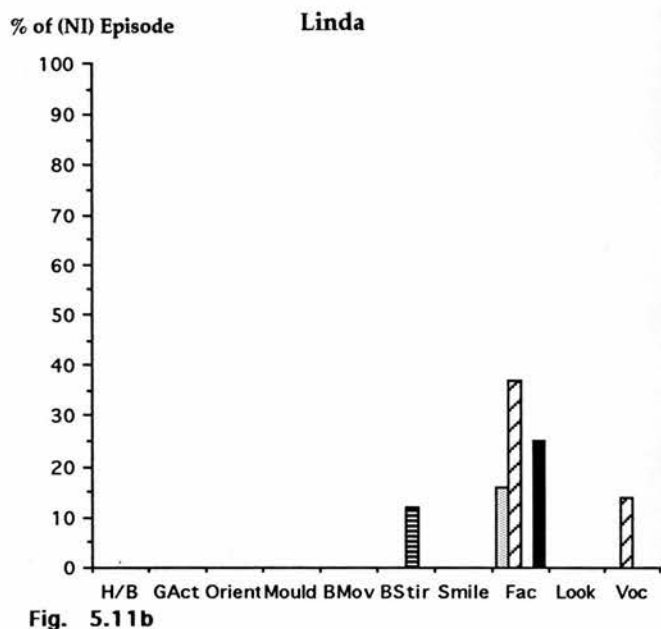
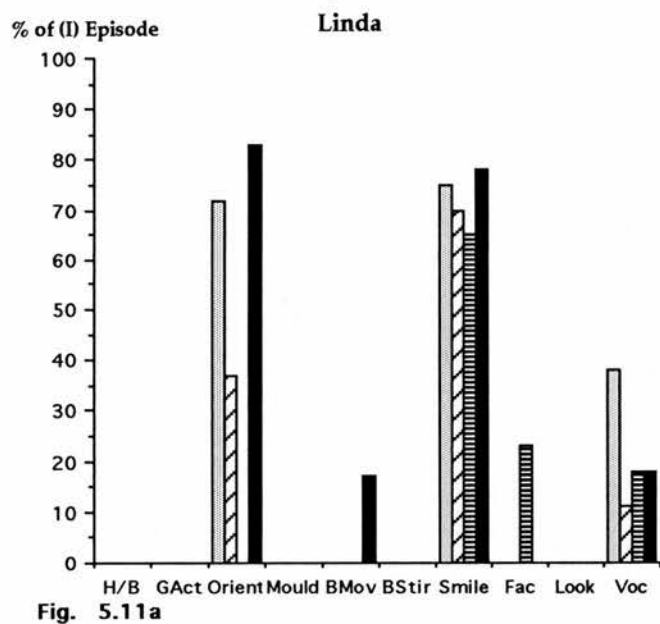
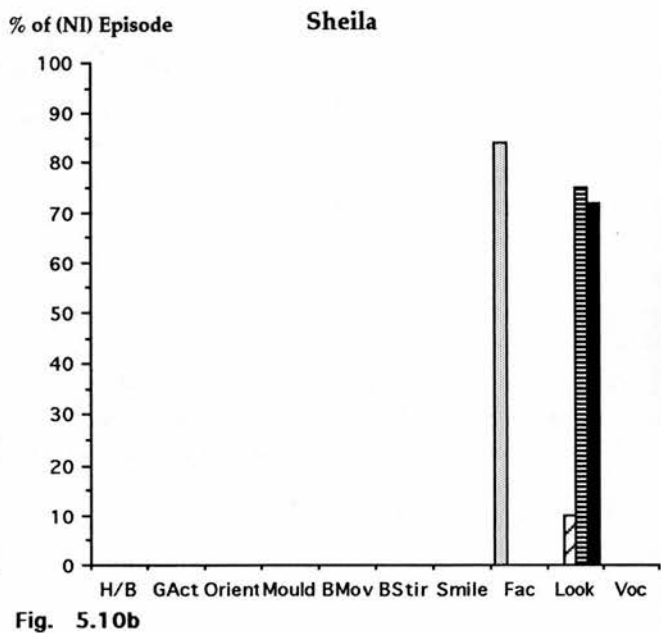
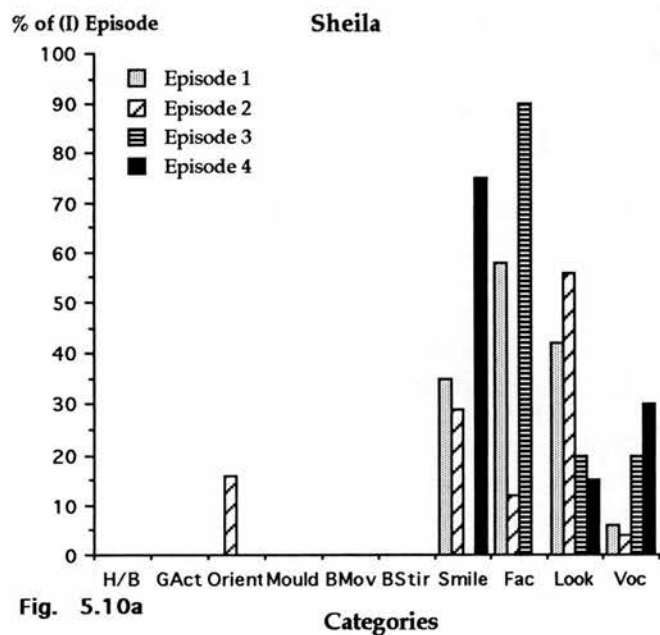
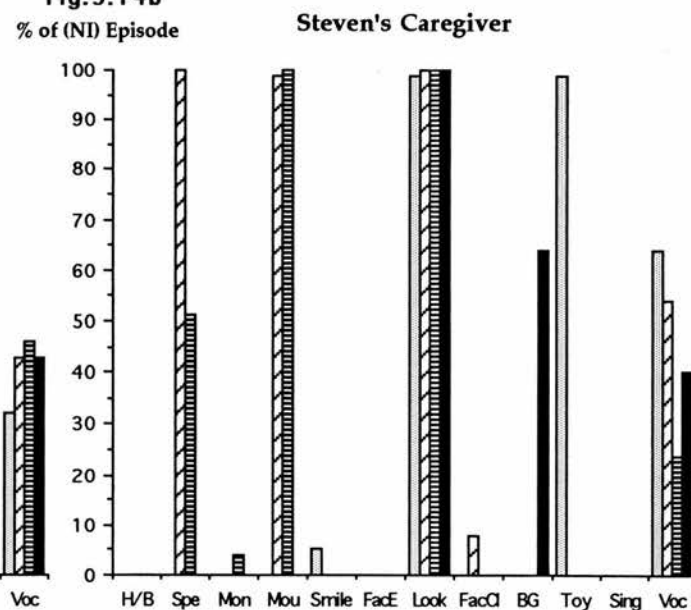
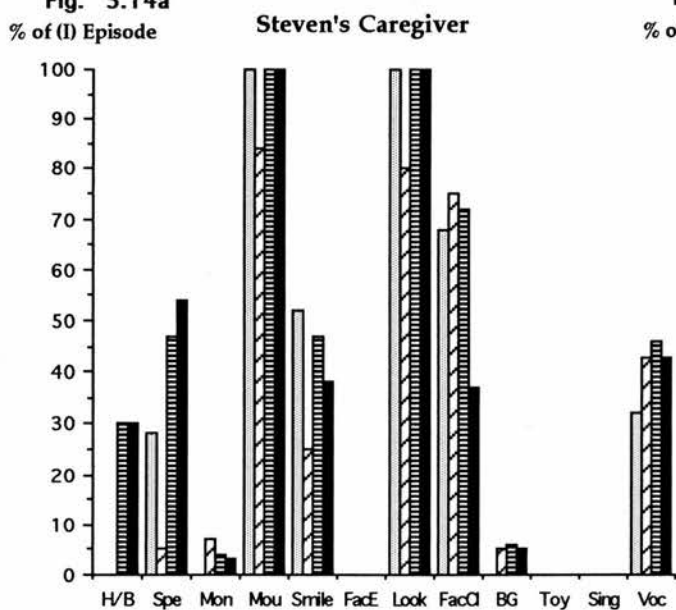
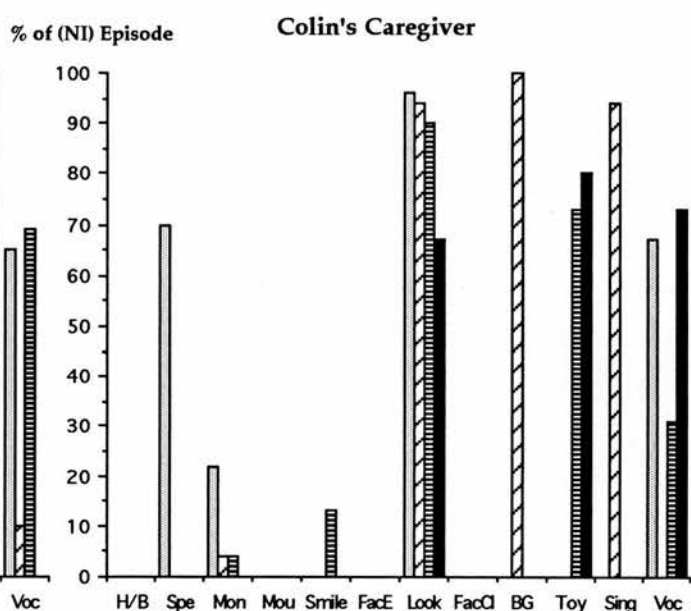
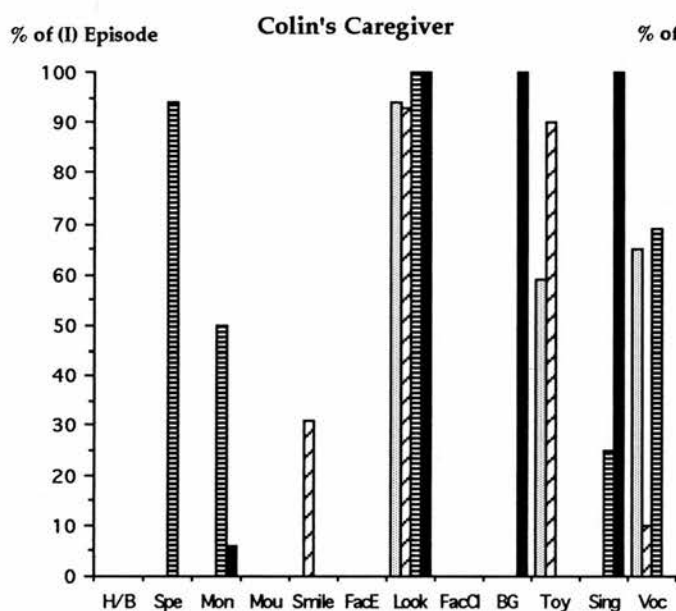
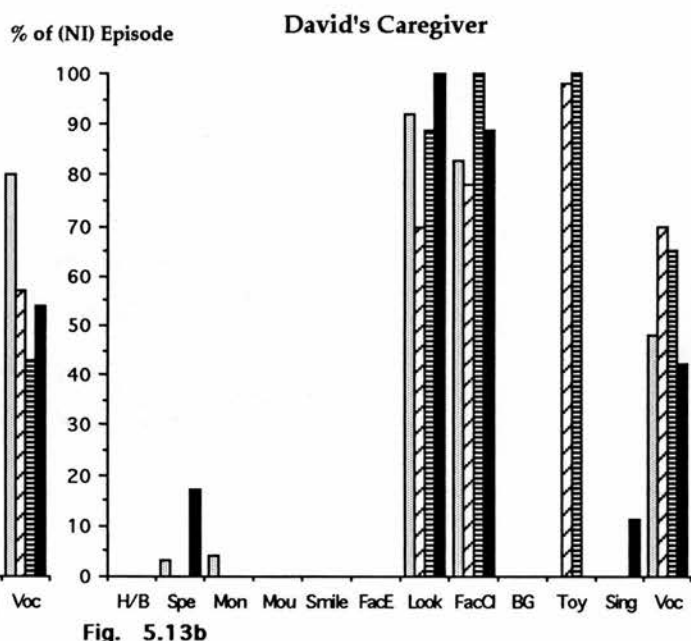
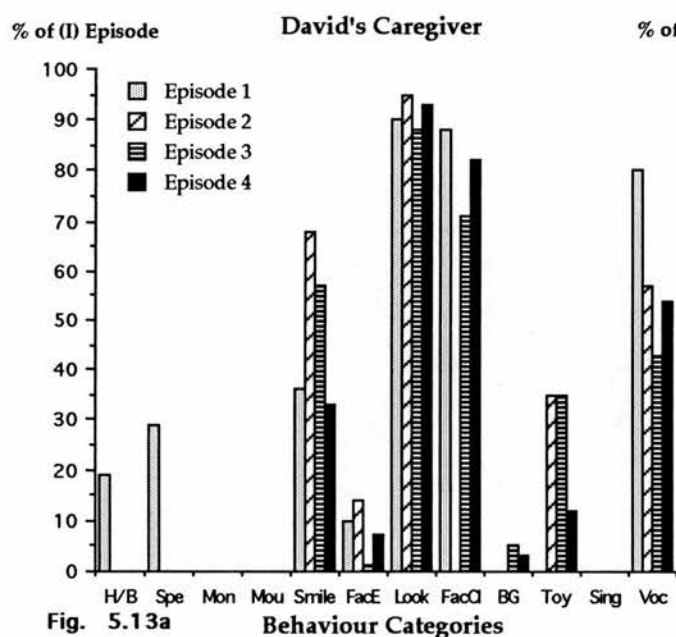


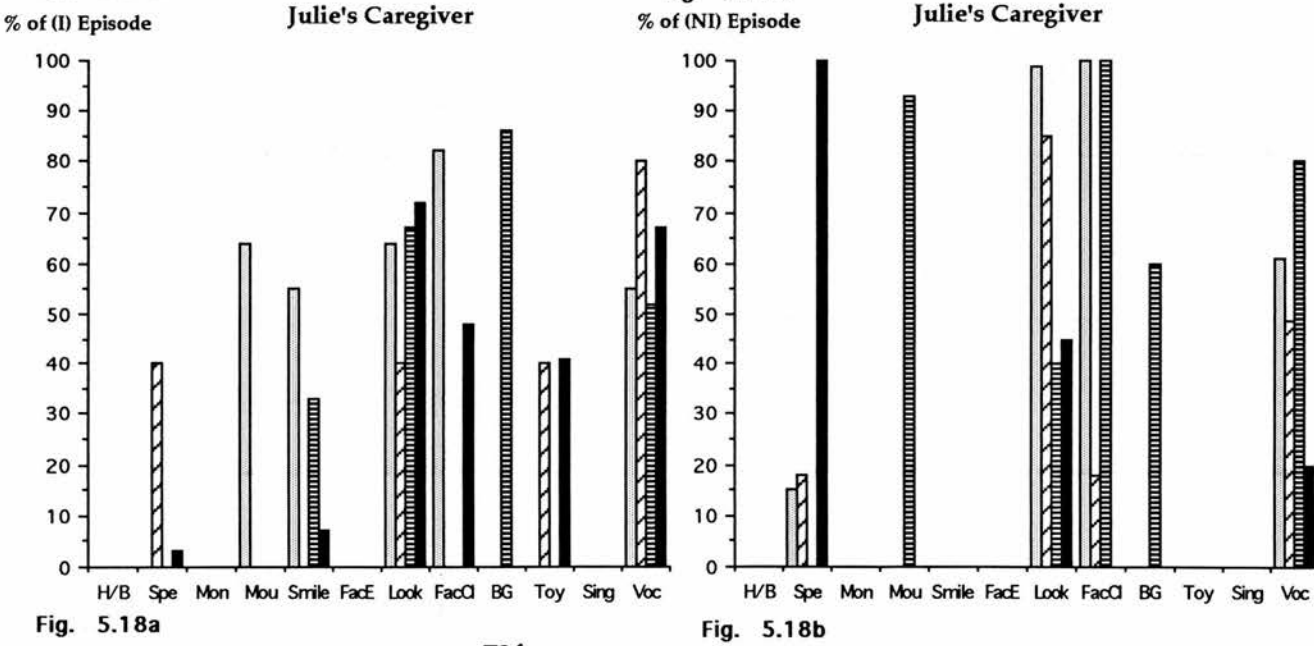
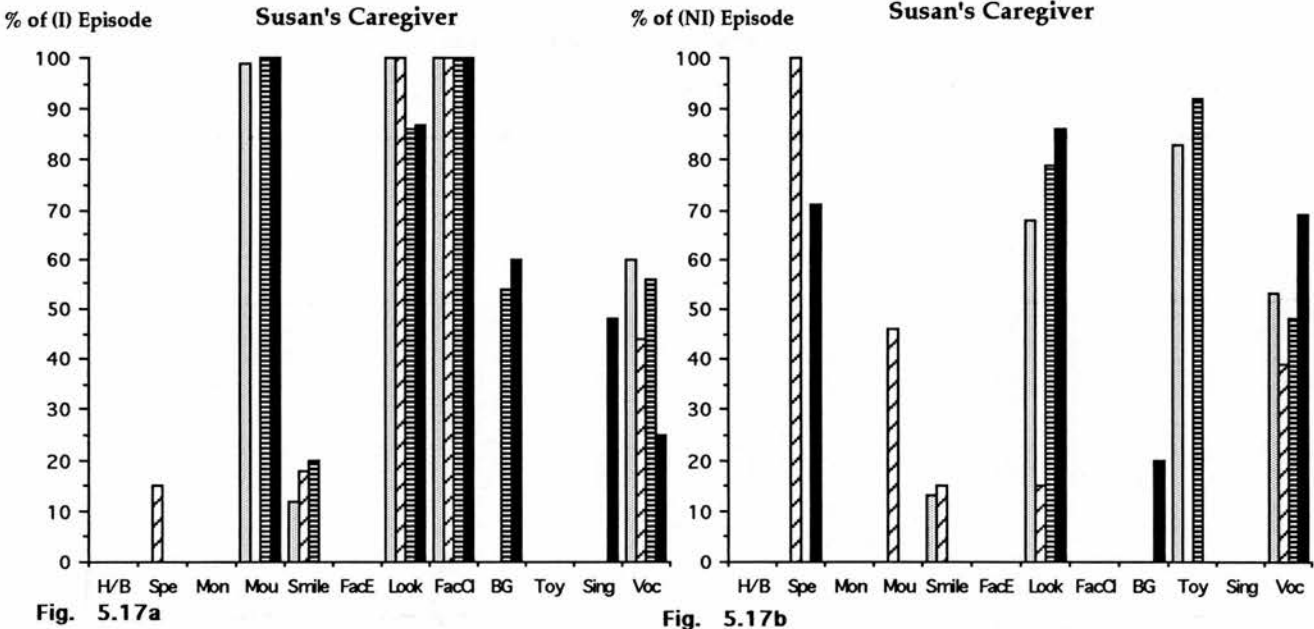
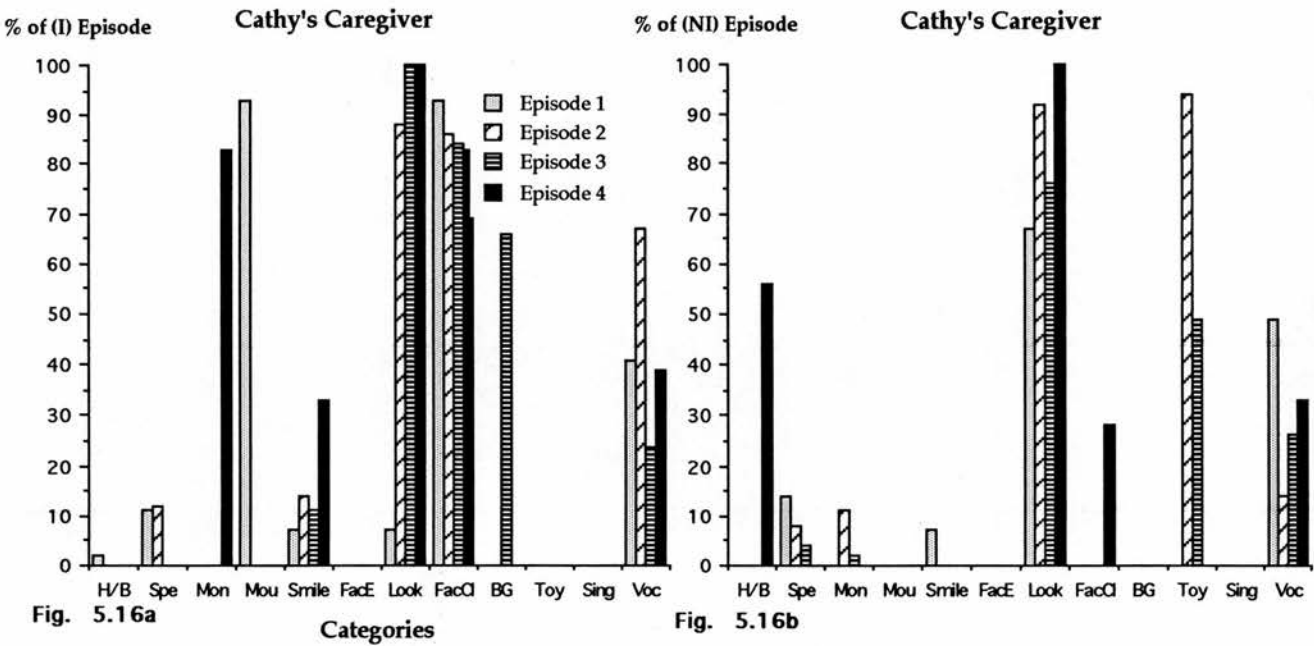
Fig. 5.3b

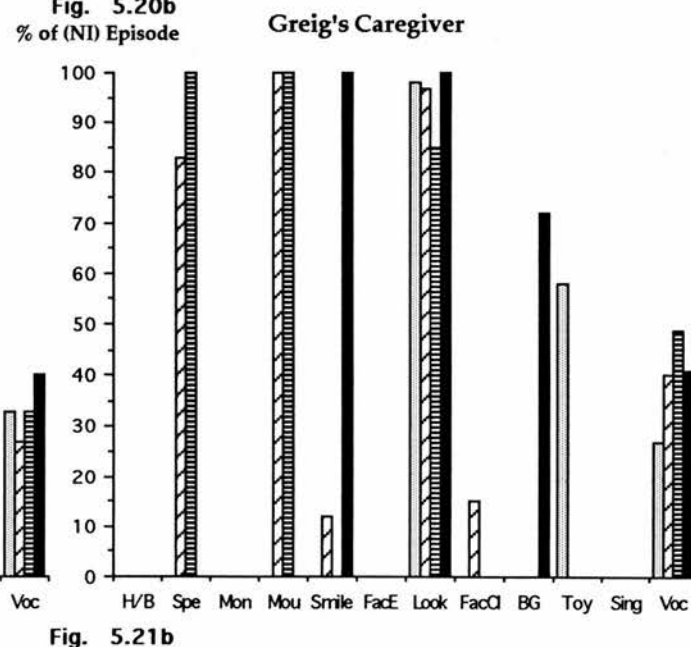
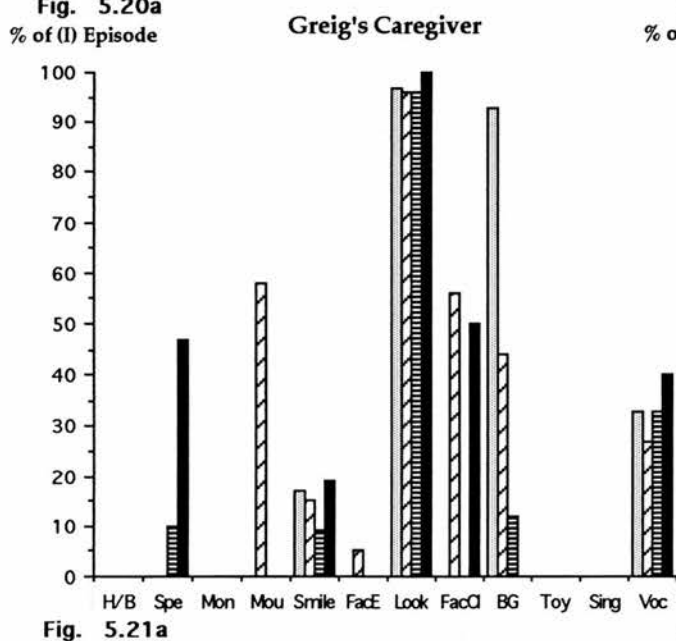
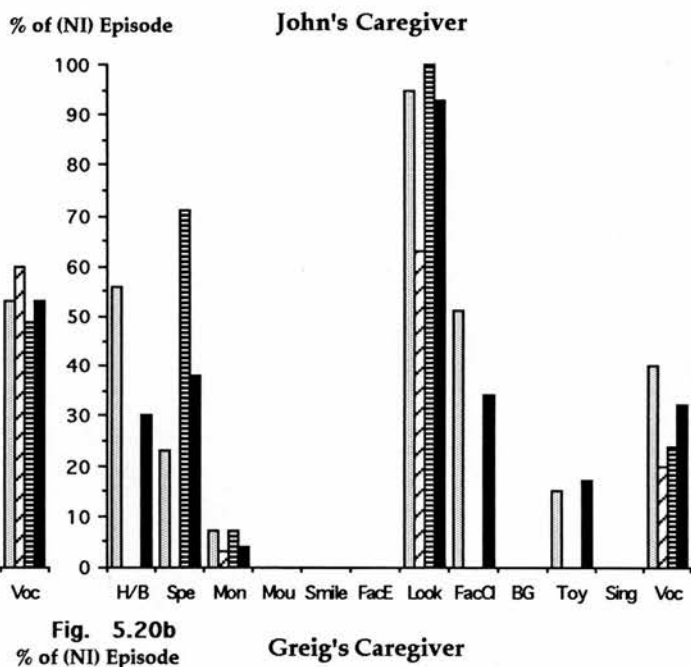
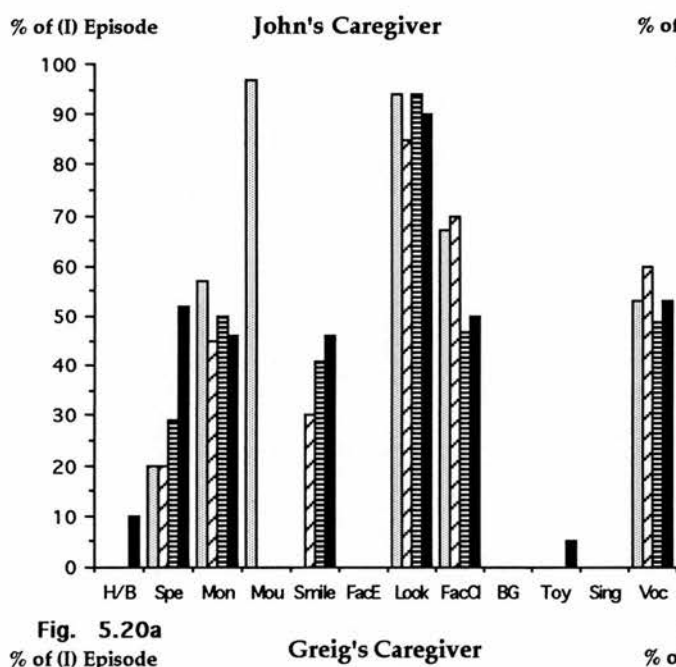
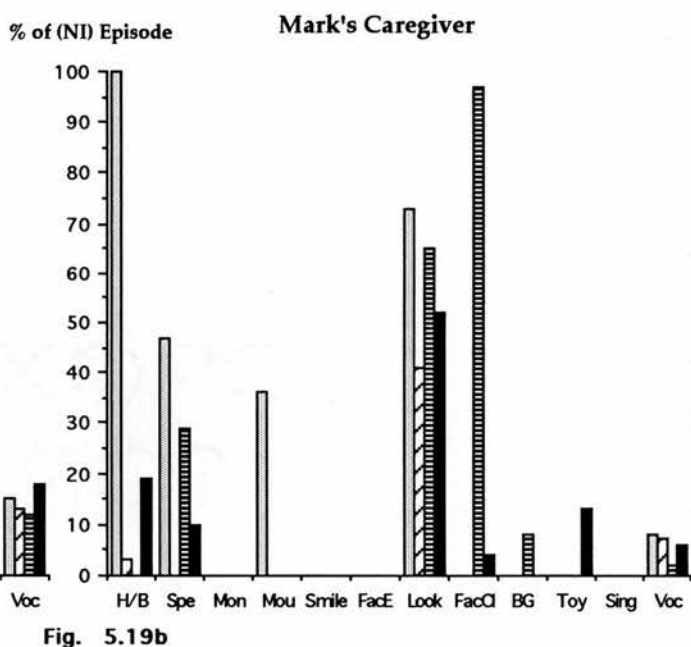
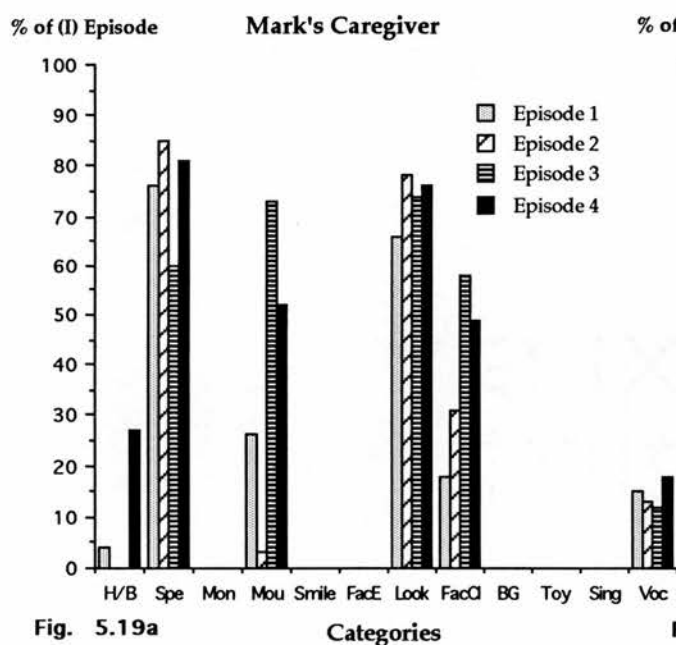












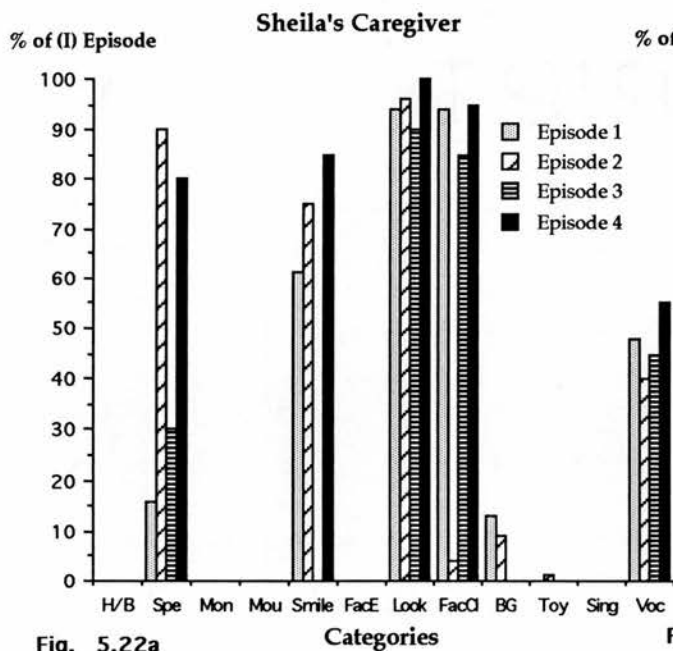


Fig. 5.22a

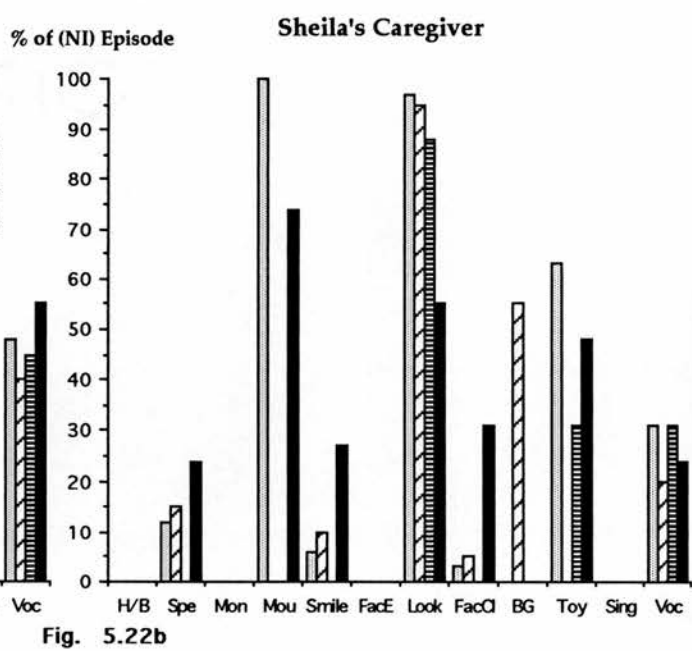


Fig. 5.22b

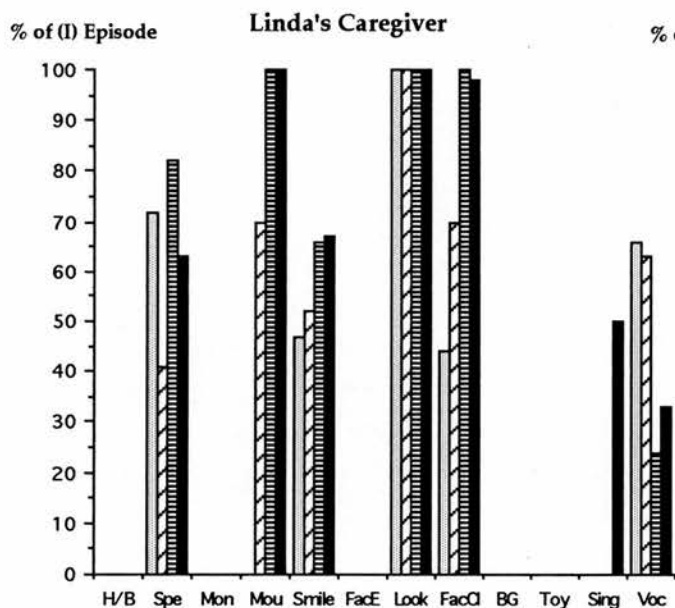


Fig. 5.23a

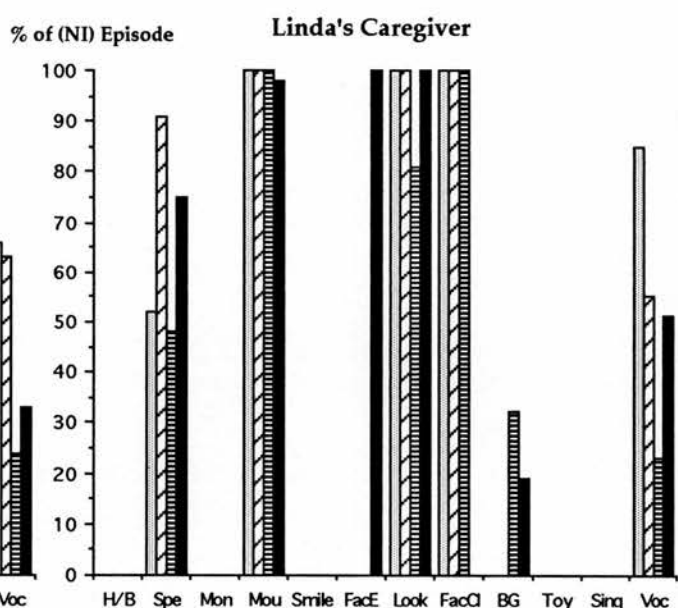


Fig. 5.23b

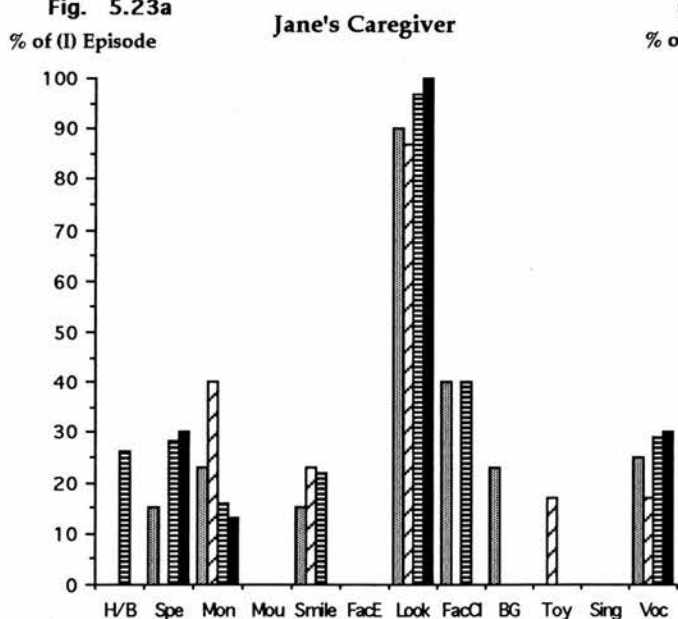


Fig. 5.24a

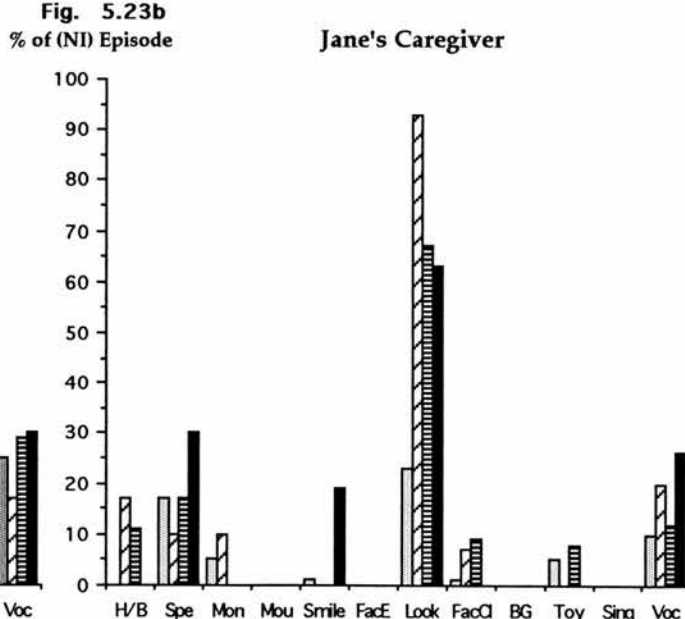


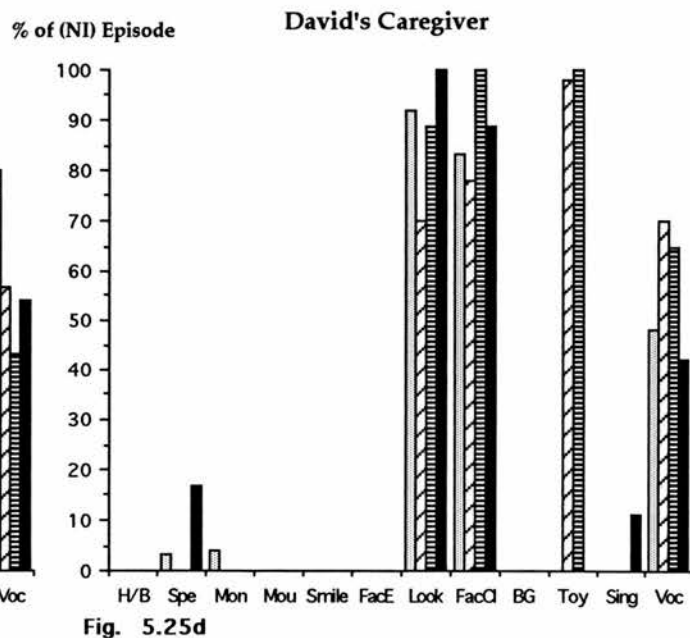
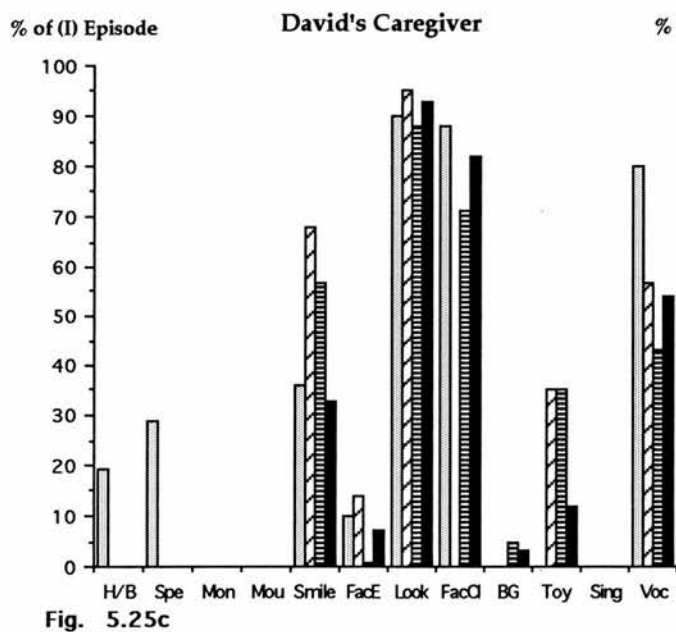
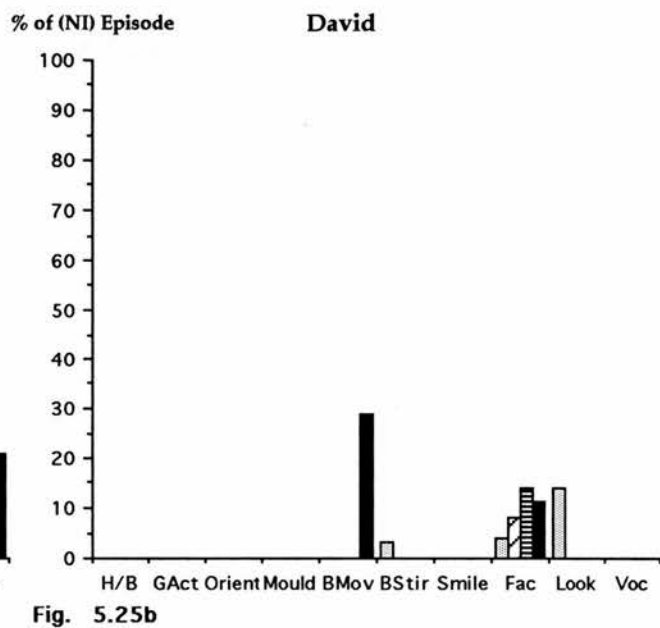
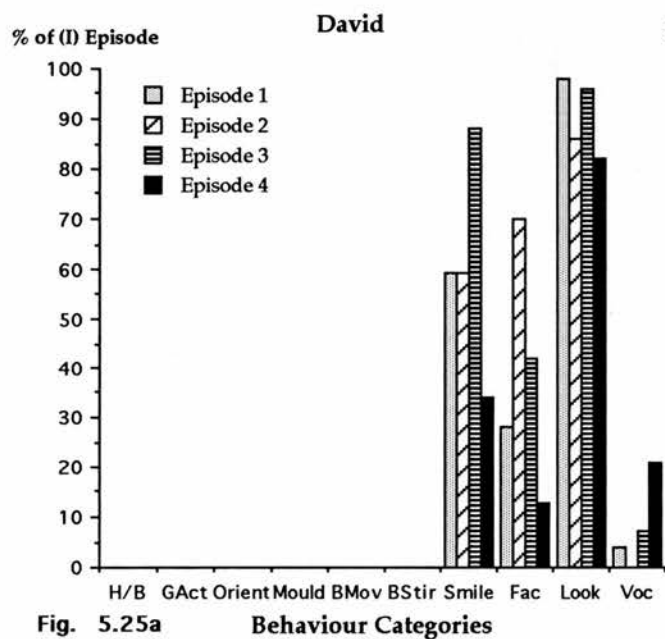
Fig. 5.24b

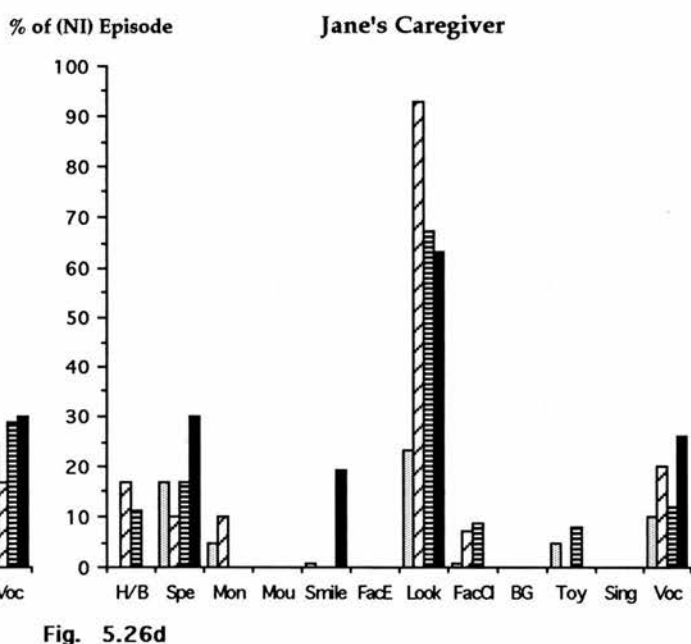
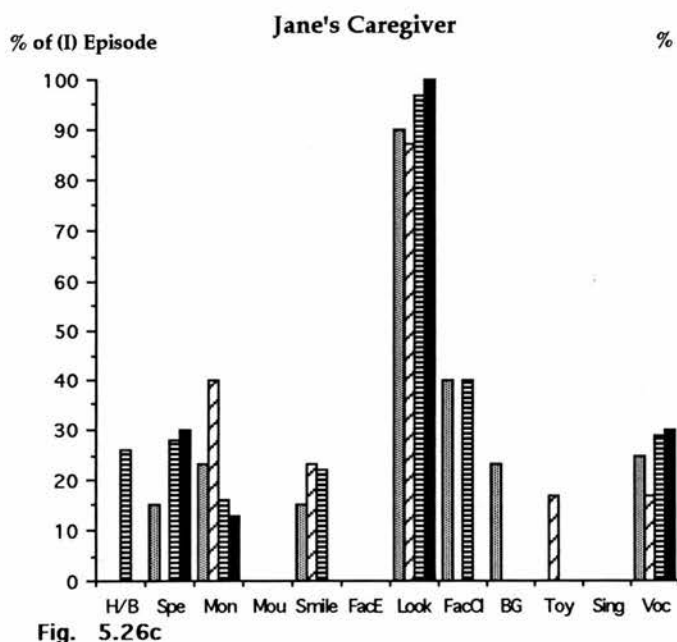
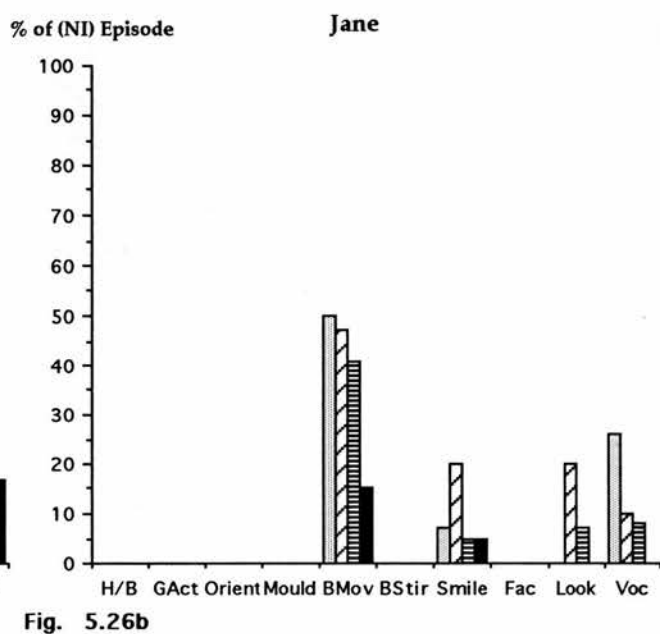
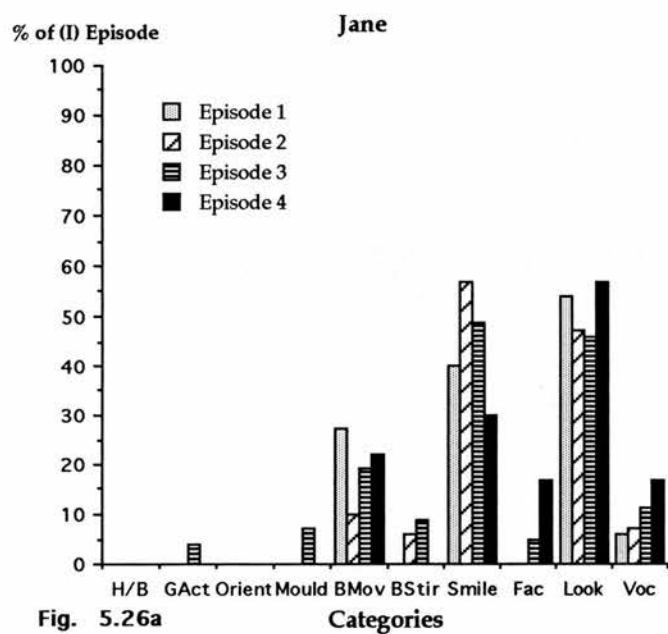
It is clear that the children showed consistent individual styles of response during episodes of 'interaction', distinct from any pattern observed in 'non-interaction' episodes. The caregivers' patterns in 'interactions' were not markedly different from periods of 'non-interaction', but the patterns between caregivers were different: they are not all employing the same range of behaviours.

These observations hold true for the children with the most and least marked differences in behaviour in I and non-I episodes, as shown in Figures 5.25a - 5.26d overleaf.

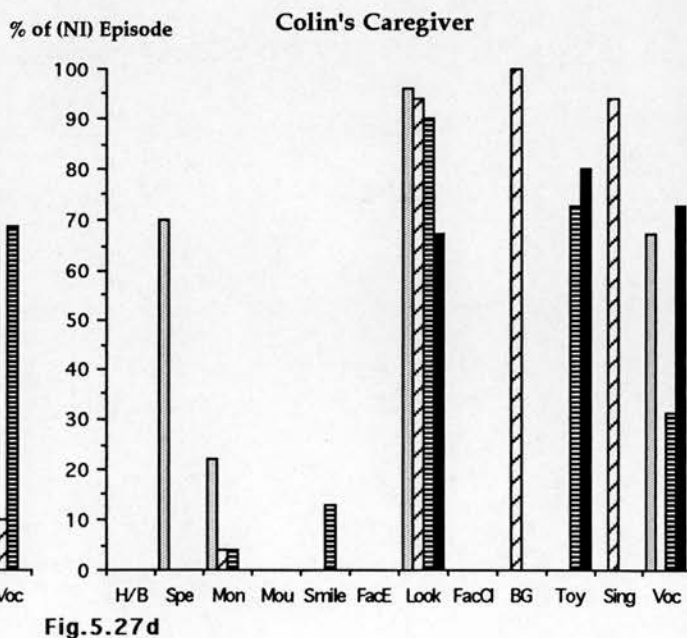
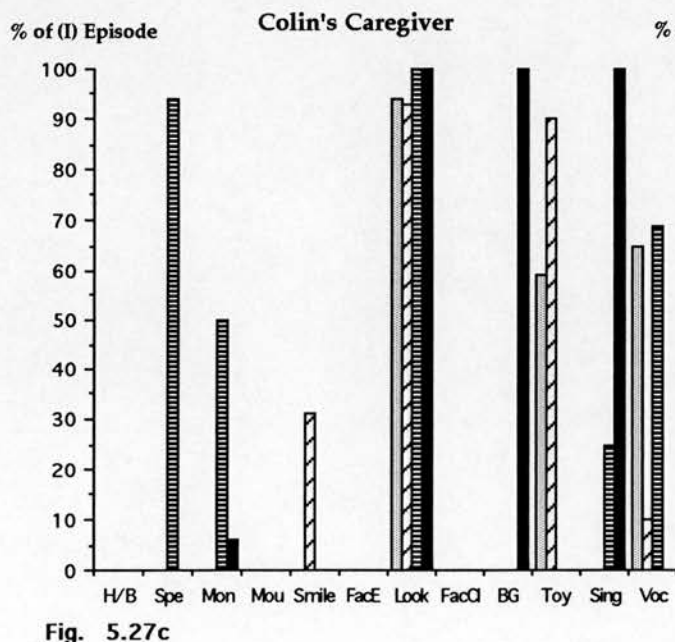
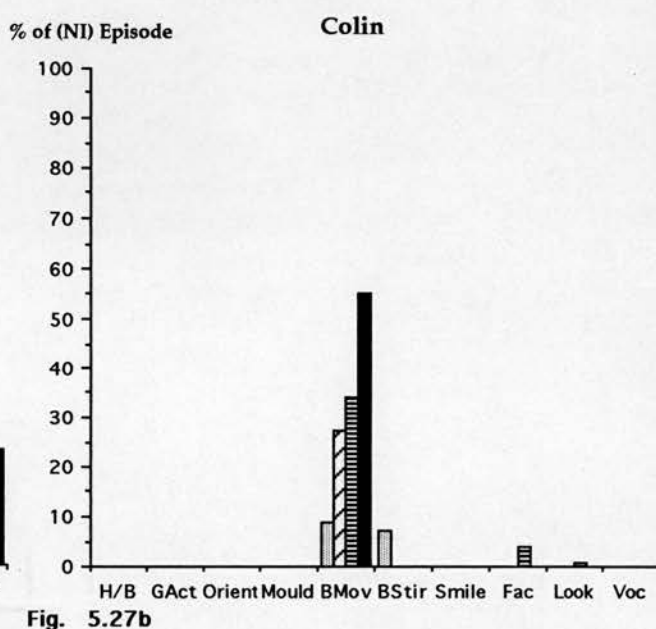
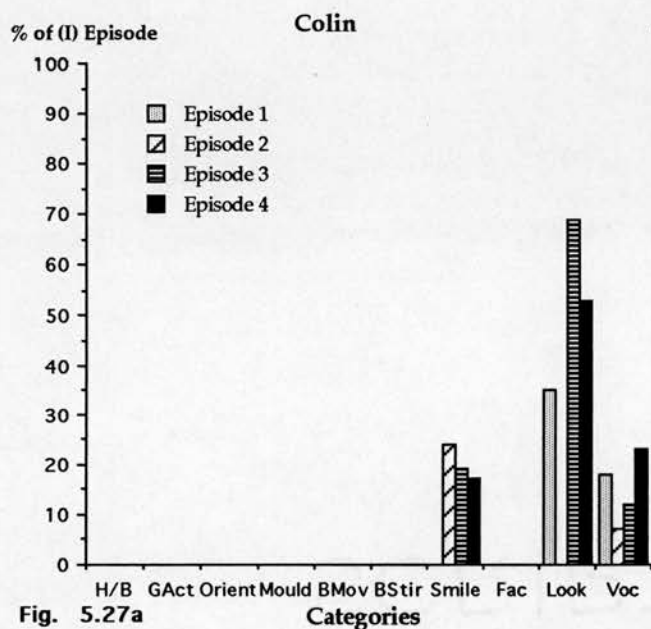
David provides a striking example of differences between I and non-I. His I episodes are full of smiles, facial movements and looks and he also vocalises. He confines his participation to these modalities. In non-I, however, he shows a marked reduction in facial movements and also looks at his caregiver in only one session and for a much reduced percentage of time. In addition, body movements and body stirring appear only in non-I. In contrast, David's caregiver does not show strong differences between I and non-I. In non-I her smiling is absent, in keeping with David's lack of smiles, and, in two episodes, her use of toys is extensive as she attempts to engage his attention, but otherwise she persists with the forms of interpersonal contact that typify I.

Jane shows much less of a difference between I and non-I than David, but nevertheless there are clear differences. In non-I her smiles and looks decrease and her body movements increase. Behaviours that appeared in I in small amounts make no appearance in non-I - 'gestural actions', 'moulding', body stirring' and 'facial actions'. Her caregiver uses many different behaviours in both I and non-I. 'Monitoring', which is a response to the child's physical activity, is greatly reduced in non-I, despite Jane's increased amount of body movement. This suggests that her caregiver is discriminating between physical activity which is 'communicative' and activity which does not play a part in the child's style of communicating - she does not monitor *all* the child's actions.





Even in a child with a narrow range of behaviours, the differences between I and non-I are apparent. Figures 5.27a - d on the next page show that Colin uses smiles, looks and vocalisations in I which disappear during non-I, to be replaced by body movements. His caregiver, however, remains very active, working hard to attract his interest. She uses many similar strategies in both I and non-I, employing the body games, play with toys, specific actions and singing that clearly gain his participation in I.



In summary, the results of this study do not suggest that the children participated readily in communication nor that the behaviours observed were frequent or elicited easily. The four episodes of interaction per child that were selected for analysis amounted to around one minute per child, in which the caregiver and child reacted and responded to each other in brief segments of time. Tables 5.8 - 5.10 illustrate the micro-timing within which the caregiver and child were conducting their communicative exchanges.

Table 5.8 Extract from Julie's recordings

Counter Numbers	Events
<u>hr min sec msec</u>	
0.00.09.09	*J's head begins to turn
0.00.09.41	*CG begins to smile
0.00.09.77	*J smiles, orients to CG
0.00.10.01	*CG's head begins to drop towards J's hand as tickles the hand
0.00.10.17	*J stops smiling
0.00.10.43	*CG brings head up, still smiling
0.00.10.77	*CG stops smiling

CG = caregiver

Table 5.9 Extract from Greig's recordings

Counter Numbers	Events
<u>hr min sec msec</u>	
0.00.02.39	*G raises body slightly and orients to CG
0.00.02.47	*CG moves towards G
0.00.03.03	*G orients further and raises body higher
0.00.04.31	*CG pulls back
0.00.04.67	*G raises hand towards CG
0.00.05.63	*CG moves her hand towards G
0.00.06.35	*CG begins to play with G's hand
0.00.06.83	*G orients as far round to CG as possible and raises body

Table 5.10 Extract from Cathy's recordings

Counter Numbers.	Events
<u>hr min sec msec</u> 0.00.04.41	*C moves arms forward for a hug
0.00.04.93	*CG moves forward in response
0.00.05.25	*CG's arms close round C
0.00.05.65	*C's arms tighten round CG

Caregivers had to work extremely hard to elicit and maintain communication, adapting their input to responses which were often patchy and unpredictable, waiting longer than is normal in social interaction for the child to respond and accommodating interruptions when the child responded 'out of turn'. On many recordings there were long periods when there was no communication between the caregiver and child. In the most extreme case one child showed no awareness or response towards his caregiver throughout a twenty-minute recording period. Nevertheless, the results do show that when the children are engaged in interactions with their caregivers, they follow an ordered system of communication regulated in time and co-ordinated with the caregiver's input. The communication is a partnership in which the actions of each partner influences the other.

CHAPTER 6: STUDY 2

METHOD

Study 2 aimed to compare the amount of communicative involvement observed between young people¹ with profound mental handicap (PMH) and their caregivers and the same young people with two groups of strangers, and to examine the nature of any differences between the communication with the three adult groups. One group of strangers had experience of working with people with profound mental handicap and the other group had no experience.

1. SUBJECTS

The subjects were six young people with profound mental handicap (aged 14-26 years) who were resident in a mental handicap hospital and 52 non-handicapped adults.

1.1 Identification and Selection of the PMH Subjects

These were residents in a unit for young people with profound mental handicap. They were selected, with the assistance of the staff, as a group who normally responded in varied ways. Two subjects enjoyed social contact, two showed little interest in others and two behaved in difficult ways with anyone who did not know them well. The five males and one female PMH subjects represented the male-female ratio of residents in this particular hospital group. The subjects had no formalised language and were unable to use manual signing or technological aids to communication. All were ambulant, but none functioned above an 18-month level in physical development. Three suffered from severe epilepsy. Every subject had attained a degree of self-help, e.g. feeding self with a spoon, drinking from a cup unaided, lifting an arm to put into a sleeve - but all remained dependent on others for basic care.

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¹The terms 'young people' and 'young person' always refer to the PMH subjects and 'adult' always refers to the non-handicapped adult subjects.

Individual young people participating in the study

Michael (aged 22 years): Michael was very active and enjoyed energetic physical play and boisterous games. He used a range of sounds to express his enjoyment and excitement, and on occasions his anger, and used many idiosyncratic actions to indicate a choice of play activity. He was affected by excited atmospheres, e.g. parties, becoming animated and noisy and appeared to enjoy general 'hustle and bustle'. He enjoyed play sessions immensely, but quickly became frustrated if the other person did not follow his expected pattern of play and did not respond appropriately to his prompts. He tolerated physical contact well, but the contact itself was not a strong feature of his communication. Michael used a number of idiosyncratic actions to prompt physical play.

Philip (19 years): Philip was a solitary, very withdrawn young person, easily upset by pressure to be involved with others and he did not appear to be interested in play or games. He rarely looked at others or showed interest in their presence. He did not like people being too close to him and was very nervous of physical contact, although he did respond well to touching that was gently and sensitively paced. Most of the time his attention was focused on a piece of string around which he had built a number of stereotyped rituals. Philip did not vocalise much, but he did have 'happy' sounds and sounds that indicated distress.

Mary (21 years): Mary had frequent spells of poor health which affected her physical co-ordination and control. Though not constantly on the move, she did like to roam around and even in ill-health would struggle to remain mobile. She enjoyed interpersonal contact, although the attention she gave the other person was often fleeting and her actions had to be watched closely to capture such moments. She was mostly silent, but did have 'happy' and 'upset' sounds. Her attentions and responses were frequently disrupted by epileptic seizures. Mary tolerated physical contact, but it was not a prominent feature of her communication.

Robert (14 years): Robert kept apart from the others, but he did not seem frightened by people being close to him, or of physical contact. In fact, it was necessary to be close to him in order to attract his attention. His span of attention was short and even when it was successfully engaged he would often suddenly break away and withdraw. He frequently vocalised, but more usually as an accompaniment to a stereotyped routine of body contact than as form of communication. He enjoyed certain forms of physical contact such as play with hands. Despite his isolated nature Robert used several idiosyncratic actions to prompt physical play.

Sean (26 years): Sean was tall and well-built. He liked being in the company of others and enjoyed watching what other people were doing. He was very responsive to people he knew well, but it did take some time to get to know him and encourage him to participate. He was often very vocal, but could also remain silent for weeks, though still remaining responsive. He was more likely to be vocal when with someone he knew. Sean responded especially well though physical contact.

Terry (18 years): Terry had physical impairments in addition to his mental handicap and, though active and mobile indoors, needed a wheelchair for longer distances out-of-doors. He was readily responsive to others and enjoyed attention and company. He was able to prompt play and communication and would do this with strangers as well as familiar people. He enjoyed physical contact and would seek physical closeness when upset, but generally it was not a strong feature of his communication. Terry used several idiosyncratic actions to prompt play and persisted when these were not immediately understood. He did not become frustrated when adults did not respond in expected ways. Nevertheless, he did become more involved when an adult played and spoke to him in familiar ways.

1.1.1 Obtaining Consent

The procedures for obtaining permission to conduct the research in the hospital has been described in Chapter 3. Consent from parents was obtained with the assistance of the senior nurse in charge of the unit. She contacted all parents first, giving a full account of the research plans and the way in which their son/daughter would be involved. On receiving their agreement to be contacted by the researcher they were sent an information sheet and consent form. As in Study 1, recording began when written consent was received. All parents who were contacted gave this consent.

1.2 Non-Handicapped Adult Subjects

The 52 non-handicapped adults were divided into three groups to provide communication partners of differing familiarity and experience. These groups were not matched for age, sex and level of training - had this been attempted, recruitment and time-tabling of recording sessions would have been extremely difficult. The overriding aim was to have three groups of adult subjects with wide differences in familiarity of contact with young people with profound mental handicap, to facilitate an examination of possible stranger effects. While acknowledging the groups were heterogeneous, they were considered to sufficiently represent appropriate differences in familiarity.

Group 1 - Caregivers (CG): Four members of the nursing staff were paired with the six PMH subjects. In pairing the young person with a caregiver an essential requirement was that they should have a well-established relationship. As it happened, two of the caregivers were each well-known to two PMH subjects. All the caregivers were female, ranging in age from early twenties to mid-forties. Two were qualified nurses and two were nursing assistants. All had worked in the unit for a minimum of three years.

Group 2 - Experienced Strangers (ES): These were 24 volunteers who had experience of working with people with profound mental handicap (e.g. care staff, teachers, therapists and activity assistants) but who were not known to the subjects with whom they were filmed. The experienced strangers, nineteen women and five men, had the widest age range (late teens to fifties) and the greatest variation in background and training of the three groups. This group was recruited with the help of colleagues in nursing, social work, education and voluntary organisations.

Group 3 - Inexperienced Strangers (IS): These were 24 final year medical students, fifteen women and nine men, who had had no previous contact with people with profound mental handicap. Students who had met any person with profound mental handicap on any occasion were excluded from the study. The students were on one-day visits to the hospital as part of a psychiatric course module. The involvement of the students was made possible by the assistance of medical colleagues.

2. PROCEDURE

2.1 Video Recording

2.1.1 General Organisation

Each PMH subject was filmed in a ten-minute recording session on twelve occasions - four occasions with the same caregiver, four times with different experienced strangers and four times with different inexperienced strangers. The session was deliberately short in order to show what it was possible to achieve in the initial minutes of an encounter.

The subjects were filmed in the studio described in Study 1, using the same camera and recording system. The same toys were present on all occasions - soft toys, rattles, squeaky toy and a ball. Adult subjects were asked to try to establish communication in any way they wished.

Recording sessions were finished early if the PMH subject showed signs of discomfort. This occurred infrequently, was expressed in mild form, and only in sessions with the IS group

As in Study 1, the researchers were based at the hospital on recording days. The other commitments of the three adult groups necessitated careful time tabling. In addition to accommodating the staff duty rotas, the caregivers worked in a very busy ward with highly dependent residents and low staffing levels. The two trained staff (a ward sister and senior staff nurse) also had to fulfil their ward responsibilities as senior nurses. The IS group were available only on the day of their visit to the hospital and the ES group had to accommodate a variety of work patterns and lengths of journey to the hospital.

Despite these organisational difficulties it was possible to achieve a workable timetable for recording sessions, due largely to the extraordinary co-operation and support offered by the hospital staff and the willingness of volunteers to fit a visit into their busy schedules, often in their free time. The day on which the IS group's visits were due formed the pivot for the timetable, the aim being to film the same young person with an inexperienced stranger, an experienced stranger and a caregiver within a few days of each other - the closest possible co-ordination of filming between the three adult groups given the many constraints on their availability. The young people, though sometimes varying in their mood from day-to-day, did not show major changes in their means of response and communication during the period of filming and so the short time lags between recordings with the different partners did not prevent comparable recordings between the IS group, ES group and CG group being collected.

2.1.2 Recording Procedures

Each IS and ES subject was given a similar introduction to the recording procedures. The introduction was aimed especially at the IS group to give them some awareness of the profound handicap of the subjects. Before their first sessions the caregivers were told what would be said to the other two adult groups and then given the same instructions.

Many people entering a ward or residential unit for residents with profound mental handicap for the first time experience a form of 'culture shock' from coming face-to-face with such extreme handicap. While it was of interest to find out how people cope in a first meeting with someone with profound mental handicap, there were ethical considerations.

First, the young person had to be protected from inept contact that might cause them distress, e.g. physically forcing a timid subject to participate. The intention was to make the experience as comfortable and enjoyable as possible for the young people, with the worst response being that they simply 'switched off', as they often do normally. Secondly, it was important that the medical students (IS group) did not find the experience so unpleasant and off-putting that they gained a negative picture of people with profound mental handicap, particularly in view of their probable involvement in the future as GP's and hospital specialists with people with profound mental handicap and their families.

Both groups of strangers were given the following introduction and instructions:-

The residents involved in the study are young people between the ages of 14 and 26 years who are profoundly mentally handicapped. They have not developed any language and so do not use words to communicate. Some are able to say a few words but they do not understand what they mean and do not use them appropriately. The residents all need a lot of help with the ordinary everyday activities of dressing, feeding and personal hygiene. They don't all behave in the same way - some like being with people and being active, others prefer to be quieter and keep themselves to themselves. The quieter residents are very able at keeping people at a comfortable distance, which prevents others from being intrusive.

As you can imagine, communication is a difficult problem and it is hard work finding out the best ways to communicate with the young people and to encourage further development. We are carrying out this study to help us describe the ways in which the young people do communicate. One of the things we want to find out is whether there are differences between their responses to people they know well and to strangers. As well as adding to our knowledge of how the young people communicate it could also provide information that would be very useful in staff training. We are also interested in finding out if prior experience of working with other young people with a similar handicap plays any part in how the young people in the study respond. To help us find out we are filming them with strangers who are working in the field and those who have not met anyone with profound mental handicap before.

We would like you to spend ten minutes with one young person in a quiet room, encouraging them to communicate, play and respond to you in any way you wish. There are no special procedures to follow, just say and do what feels right at the time. Although the young people won't speak, you can speak to them if and when you would like. In the room there are toys which you can use if you want, a wall-mirror, a play mat and some chairs. It doesn't matter where you are in the room and whether you move around or not - do and say what you feel is right for the young person.

2.1.3 Filming Guidelines

Where possible, both PMH subject and non-handicapped adult subject were included in the picture. Most filming was done with the main camera in the adjacent recording room, using the criteria described in Chapter 3.

The subjects in Study 2 were all independently mobile, though not all chose to be active, and, in this study, the remote controlled camera was used more frequently to track the more active subjects as they moved round the room. There were many more occasions in this study when it was necessary to use split-screen filming. This, however, was only acceptable if one subject (usually the adult) remained in a small area of the room. When both adult and PMH subject were moving actively round the room some distance apart it was difficult to co-ordinate the pictures on the split-screen. On these occasions the camera focused on the PMH subject. Sometimes the PMH subjects moved into the one corner of the room which could only be covered by the remote camera and remained with their back to the camera. On these occasions the camera focused on the adult.

After filming was completed, all of the IS group were shown the tapes, and they discussed the events on the screen and expressed their opinions and feelings about their involvement. This was a form of teaching and critical self-appraisal familiar to the students in the IS group. The aim was to encourage positive discussion which could help to them cope with other people with PMH that they might meet. It was hoped that they would gain some understanding that, in their own way, the young people were capable of communicating despite their handicap. The students' participation in these discussions gave encouragement to the idea that some degree of understanding was indeed achieved.

The ES group were offered the same opportunity to view the recordings. There were time constraints for many who were unable to prolong their visit, but some were able to watch and provide additional information about their participation.

The CG group rarely had time to watch the recordings immediately after the session, but there was always a brief discussion to gain a picture of how typical the behaviour of the young person had been. Although the young people's moods varied between sessions, the caregivers considered the recordings provided a typical picture of the young people in any given mood. Caregivers subsequently reviewed all the recordings, as described in the next section.

2.2 Video Reviews with Caregivers

The caregivers reviewed the recordings in the recording room at the hospital and were asked to select the moments when they felt the young person to be aware of or reacting to the adult's presence and to describe the behaviours they considered to be communicative. Anecdotal information was also collected, providing general descriptions of the young person's means of communicating and responding. The researcher was based in the hospital all day when reviews were timetabled, to allow an essential flexibility for nursing staff involvement.

Review 1

The four hospital caregivers reviewed all twelve recordings of the young person(s) they partnered, and they indicated where they judged the young person to be responding in some way. The beginning and ending of each segment was noted using the digital time counter inscribed on the tape. The aim was to obtain a spontaneous reaction and, unless otherwise requested by a caregiver, all observations were made with the tape playing at normal speed. On occasion, when they were uncertain about a response, caregivers did ask for sections to be replayed or that the

speed be slowed down . The usual outcome of this was a confirmation of their initial observation. A second more detailed review was conducted on half of the sample when all the recordings for each PMH subject had been reviewed.

Review 2

Two recordings from each of the adult groups were reviewed a second time (6 per young person) to gain more detailed information and descriptions of communication. The session was conducted as follows:-

- i. The tape was stopped at the beginning and end of each of the segments selected during the first review, and the caregiver was asked to describe the events that determined her selections. The tape was replayed as often as necessary for the caregiver to make a decision. The replays served more to help them to find the words to describe events rather than to pinpoint or confirm their previous choices. No caregiver disagreed with her original selection in Review 1.
- ii. The caregiver was asked to view the segment a second time and rate the young person's level of involvement based on the same criteria for the reviews by parents in Study 1².

The example in Table 6.1 shows how the caregivers' selections of awareness and communication in Review 2 were noted. The first counter number of each pair refers to the beginning of some form of awareness while the second refers to its termination. The corresponding text describes the on/off cues identified by the caregiver. Only moments that were judged to show some form of awareness or involvement are noted.

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²**Aware:** The child is a spectator. He/she shows awareness of his/her mother or gives her some attention, but does not get involved in what she is doing.

Involved: The child is a passive participant. He/she responds to what his/her mother is doing with actions and sounds, e.g. smiles, vocalisations, reaching out, turning head towards mother.

Very Involved: The child is an active participant. He/she not only responds to the mother, but plays a part in keeping the interaction going, or initiates contact.

Table 6.1 Example of Coding sheet for Review 2

Involvement	Counter Nos.	Cues
Aware	<u>hr min sec msec</u> 0.59.05.58} starts 0.59.44.22} ends	*allows adult to take his hand *turns away from adult and takes hand away
Aware	0.59.56.74} starts 1.00.41.18} ends	*allows adult to take his hand *his head goes up and mouth opens as adult lets go of his hand. PMH subject does not try to re-establish contact
Aware	1.01.17.38} starts 1.01.56.40} ends	*turns to watch what adult is doing *takes adult's hand
Involved	0.01.56.40} starts 1.02.04.40} ends	*PMH subject has become more involved - he took the adult's hand *Adult takes his (adult's) hand away
Aware	1.02.04.40} starts 1.02.30.78} ends	*PMH subject stays beside adult, but does not try to take his hand again *head goes up, gazes above adult's head and 'freezes'
Aware	1.03.31.10} starts 1.03.45.52} ends	*accepts toy being placed on his hand and half glances at it *head goes up, mouth opens

3. CODING AND ANALYSES

The shortest session lasted six minutes and, therefore, the first six minutes of each of the 72 recording sessions was selected for analysis. Recordings were observed at normal speed, although slow motion and frame-by-frame advance were used frequently to determine the precise beginnings and endings of events. The approximate rate of coding was 3 hours for each session.

3.1 Coding

The aim was to develop coding which would yield information about the group as a whole, but could accommodate the idiosyncratic and often strange behaviours of the PMH subjects. Therefore, it seemed appropriate to allow the events on the video recordings to shape the coding schedule, rather than using a pre-determined list.

A coding schedule was developed which covered all events within the period of analysis, including solitary and non-communicative activity. The schedule was developed and piloted over a twelve-month period and was designed to capture events which would indicate different forms and levels of shared involvement between the young person with profound mental handicap and a non-handicapped adult partner.

3.1.1 Development of Coding Schedule

During the initial stage of development, recording sessions were previewed to gain an impression of the kinds of events which typically occurred. Descriptive notes were made from observations of all six subjects in sessions with each of the three adult groups. Broad headings began to emerge which enabled the descriptive notes to be refined and ordered, thus providing the first draft of the schedule. The draft was applied to samples of recordings of all subjects, adding codes when a segment of the recording could not be coded under the existing descriptions. This second draft made it possible to segment the stream of events in greater detail and to develop consistent rules for determining the beginning and ending of events. A third draft allowed events occurring within the same time period to be separated into main events and secondary events.

At this stage, inter-rater checks were carried out to test the efficiency of the definitions, using a rater experienced in working with people with profound mental handicap. The checks yielded points of substantial disagreement, and the researcher and the rater reviewed the recordings together to determine the source(s) of disagreement. The reviews

revealed that the disparity arose from the wording of definitions rather than dispute about concepts, and a fourth draft with revised definitions was compiled.

In particular, the following were more precisely defined: the rules for beginning and ending events; classifying co-occurring physical contact events; definitions for 'glancing', 'accepting a toy', 'interpersonal reaction when accepting a toy'; and a more precise distinction between 'mutual games' and 'interactive involvement'.

The rater coded two-three minute samples from a further six recordings (one per subject) using the fourth draft. The percentage agreements reached between the rater and researcher in the four categories were 83% (Solitary Activity), 80% (Focus on Toys), 87% (Physical Contact) and 87% (Person-to-Person). After rating the recordings, the rater discussed the transcriptions with the researcher, referring to the video recordings where necessary. On this evidence, the initial problems appeared to be remedied, and it was decided to proceed with this version of the schedule for the main analysis.

In sessions filmed near the end of the recording period, several physical contact behaviours were observed that were not present in the earlier recordings. These behaviours were added to the Physical Contact category, with a different coding label to avoid disrupting the sequence of coding and transcription which had been already completed.

3.1.2 Description of Coding Schedule

The schedule³ was divided into four categories, based on the PMH subject's responses:-

Solitary Activity (5 codes)

This category reflects different types of intervention by the adult in which the young person gives no response or signs of awareness that there is anyone else in the room. For example, the adult might move a young person from one position to another, offer a toy, or call his/her name, during which there is no change in what the young person is doing.

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³A full version of the schedule is included in appendix 2

Focus on Toys (5 codes)

In this category the adult's attention is focused principally on a toy and, if he or she responds, the young person's attention is also focused more on the toy than the adult.

Physical Contact (29 codes)

This category refers to physical contact in which the young person is free to move away or disengage, if he or she wishes, thus confirming that any involvement through physical contact is a voluntary act and something the young person wants to do. The coding had to capture many different forms of touching; e.g. passive hand holding, patting a limb, leaning against each other, leading to greater number of codes in this category.

Person-to-Person (6 codes)

The attention of the adult and young person is focused mainly on the other person and their non-object actions and nonverbal communication. Occasionally toys might be included, but they are not the focus of attention for either participant.

The categories indicate the *form* of involvement, e.g. physical contact. Judgements on the *level* of involvement between PMH subject and adult are made within categories, e.g. hand games initiated by the PMH subject are judged as more involved than passive hand-holding initiated by the adult. The categories are not necessarily mutually exclusive, e.g. a subject can engage in person-to-person contact in which there is also play with toys, but they are made independent by definition to preclude the same event being recorded under different headings. Items within categories are similarly defined to render each independent of the other. The reliability checks showed good agreement in the judgements made according to these definitions.

Main and Secondary Events: All events occurring within the six-minute period of analysis were transcribed and onset and offset times noted. The event judged to be the principal event of interpersonal significance was recorded under the heading 'main event'.

Physical contact is noted as a *main* event where it occurs in the *absence* of either Focus on Toys or Person-to-Person. Co-occurring physical contact events judged to be ancillary to the main event are recorded as 'secondary events'. This enables all instances of physical contact to be noted so that its form and prevalence can be compared between the three adult groups. An example of a recording sheet is illustrated in Table 6.2.

Table 6.2 Example of a coding sheet using the Shared Involvement schedule

Main Events			Secondary Events		
Counter Numbers	Code	Comments	Counter Numbers	Code	Comments
0.49.02.29} 0.49.23.93} [21.64 secs]	1i	Ends as PMH subject's left hand reaches up for toy			
0.49.23.93} 0.49.30.69} [6.76 secs]	2o	Ends as PMH subject begins to clap hands in response to adult's clapping and raises head to look at adult. PMH subject -T *(T = Terminates)			
0.49.30.69} 0.50.29.53} [48.84 secs]	4b	Ends as PMH subject turns to left, turns head away from adult, picks up rattle. PMH -T	0.50.08.43} 0.50.14.48} [6 secs.05]	3e	Adult pats PMH subject's closed hands, Begins as adult's R. hand touches PMH sub. Ends as Adult's R. Hand leaves PMH subject.
0.50.29.53} 0.50.55.53} [26 secs]	2c	Ends as PMH subject drops toy and turns L shoulder away from adult			

Although some codes yielded few observations, the system enabled each PMH subject's individual participation to be logged. The schedule was designed to provide as many 'hooks' as possible to capture idiosyncratic and disparate events from the passing stream of behaviour (as described by Bakeman and Gottman, 1986), and to catalogue them systematically under independent categories. Within categories, it was possible to establish a sub-coding of events that, to a degree, reflected the PMH subject's level of involvement. Once the recordings were catalogued in this way the transcribed data were regrouped within a reduced category reflecting a hierarchy of involvement, in preparation for statistical analysis.

3.2 Reliability

Interrater reliabilities were obtained for the four main categories and the individual items within categories using the same formula as in Study 14.

Randomly selected three-minute segments were rated from recordings of each of the six PMH subjects with an IS, ES and CG adult. The raters were required to agree on the event taking place, and to show agreement on the beginning and ending of the event within a five-second period. The raters were required to judge the principal events and all co-occurring events observed in the same time period. The independent rater who conducted the checks during the piloting of the schedule also carried out the rating of the main analysis.

Overall agreement on the categorisation of events under the main headings, i.e. Solitary Activity, Focus on Toys, Physical Contact and Person-to-Person, regardless of agreement on sub-coding, was 91%. The agreement on events within categories ranged from 70 - 94%, with reliabilities of 84% (Solitary Activity), 81% (Focus on Toys), 81% (Physical Contact) and 82% (Person-to-Person) for the four main categories. A simple comparison of total observations was made for events which occurred infrequently in the selected segments. The agreements for individual events are listed in Table 6.3.

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⁴ $R_{occ}\% = \frac{\text{Number of observations raters agreed behaviour occurred}}{\text{number of observations either rater scored behaviour}} \times 100$

Table 6.3 Reliability Agreements

Event	%Agree	Event	%Agree
Self-Absorbed Behaviour	94	IHBAA	76
Passive Acceptance	88	IHHAA	85
Postural Adjustment	79	IBCAA	80
Rejects	*6/6	IHHSA	84
Watching	82	IHBBA	77
Accepts Toy	86	IHG	88
Toy Interpersonal	79	IBCBA	80
Mutual Involve - Toy	85	LA	83
Offers Toy	78	LS	84
Offers Toy Involved	83	LB	84
HBMR ⁵	88	SPE	88
HHMR	91	ACTA	77
BCMR	90	ACTS	70
HBAA	91	ACTAB	78
HHAA	87	ACTSM	72
BCAA	85	Non-Verbal Reacts	85
HBSA	76	Mut. Involve (A. Init)	81
HHSA	79	Interact Involve (A. Init)	86
HBBA	78	Non-Verbal Initiates	79
HG	90	Mutual Involve (YP Init)	80
BCBA	80	Interact Involve (YP Init)	83
IHBMR	82	Missed Toy Offer	*3/3
IHHMR	85	Missed Cue	*4/3
IBCMR	88		

*The number of events observed by researcher and rater - Res/Rater.

3.3 Reduced Category System

The 45 codes from the original schedule were collapsed into five mutually exclusive blocks⁶ that indicated different levels of involvement observed between the PMH subject and non-handicapped

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⁵The abbreviations are explained in the *Shared Involvement* coding schedule

⁶The Table in appendix 3 shows the assignation of the original codes to the five blocks.

adult communication partners. The levels of involvement ranged from 'Alone' to 'Reciprocal Engagements':-

Alone

Activity coded as 'Alone' indicates no involvement with the adult. There is no physical contact, except where there is 'rejection' of the adult's actions. Though 'rejection' is a deliberate act involving contact with the adult, the subject's aim is to terminate any involvement with the adult and to be alone.

Acknowledge

The PMH subject acknowledges the presence of the adult (e.g. watches at a distance, but does not move closer to participate in the activity), or reacts once to the adult's presence or intervention (e.g. looks and smiles simultaneously, then discontinues his or her interest).

Passive Involvement

The PMH subject does not become actively involved, but remains in physical contact with the adult. This category covers all forms of physical contact coded as a 'main event' where the PMH subject does not actively participate, but also does not try to stop the physical contact.

Active Involvement

The PMH subject participates with actions and sounds in response to the adult, showing interest in toys presented by the adult and observably reacting to the adult, or initiates contact or offers a toy, but does not reciprocate further. Physical contact coded as the 'main event' in which the subject is actively involved is also included (e.g. hand play). Unlike similar play in a 'reciprocal engagement', the subject does not acknowledge the adult in other nonverbal ways. During 'Active Involvement' the actions of the adult and PMH subject are usually in parallel, rather than to-and-fro as in 'reciprocal engagements'.

Reciprocal Engagements

The PMH subject participates with actions and sounds in two or more consecutive exchanges with the adult, during which looks, smiles, body orientation and vocalising directed at the adult are observed.

3.4 Statistical Analyses

Levels of Involvement

A total number of 2,221 observations were made of 'main events', with a range of 243 - 616 observations for the individual PMH subjects. In addition, there were 314 observations of co-occurring 'physical contact' events, ranging from 26 - 88 observations for individual subjects. The observations were grouped into the five categories described above:- 'Alone', 'Acknowledge', 'Passive Involvement', 'Active Involvement' and 'Reciprocal Engagements'. This allowed the levels of involvement of the PMH subjects with the three adult groups to be compared. Comparisons were based on the percentage of time spent by the PMH subjects in each category during the six-minute period of analysis.

Statview was used for statistical analysis, as in Study 1. The levels of significance reported in the results chapter are those obtained from Statview. Significant results are summarised in Table 7.6 of the next chapter at or below the .01 and .05 levels of significance.

The proportion of time spent by the PMH subjects in the five levels of involvement when with the three adult groups was compared. A Friedman within-subjects analysis of variance was conducted to determine whether there was an overall statistical difference between the amounts of involvement elicited by the three groups. Wilcoxon matched-pair signed-ranks two-tailed tests were used to find out where any group differences might lie.

Caregiver Reviews

The proportion of time in which the PMH subjects were judged to demonstrate an awareness of the adult's presence was calculated. Group comparisons were conducted using a Friedman within-subjects analysis of variance, followed by Wilcoxon matched-pair signed-rank two-tailed tests to locate any significant differences between the groups.

Physical Contact

The acceptance, tolerance and initiation of physical contact was used to provide further indication of the PMH subjects' involvement. All

instances of physical contact were coded and the cumulative amount (in seconds) observed in each session was calculated to obtain a total for each of the adult groups. The totals were compared across the three adult groups using a Friedman within-subjects analysis of variance and Wilcoxon matched-pair signed-rank two tailed tests.

Individual Profiles

Profiles were compiled from statistical and anecdotal information for each PMH subject, presenting their individual ways of responding and participating in communication.

CHAPTER 7: STUDY 2

RESULTS

1. SHARED INVOLVEMENT

The percentage of time the group of PMH subjects spent in five hierarchical levels of involvement was compared across the three groups of adult subjects: Inexperienced Strangers (IS), Experienced Strangers (ES) and Caregivers (CG).

1.1 Alone

The mean percentage of time the PMH subjects spent in the 'Alone' category, in which there was no observable interpersonal or physical contact between the young person and adult, was computed. As Table 7.1 shows, the greatest amount was observed when the PMH subjects were with the inexperienced strangers and the least when they were with their caregivers. A Friedman within-subjects analysis of variance yielded an overall significant difference between the groups, ($\chi^2(2)$, $p=.0057$). Using a Wilcoxon matched-pairs signed-ranks test, the greater percentages of time the PMH subjects spent in 'Alone' with both groups of strangers in comparison with the CG's were shown to be significant, ($p=.0277$). A significant difference was also found in the greater percentage observed with the IS group compared to the ES group, though at a reduced level, ($p=.0464$).

Table 7.1 Percent of Time Spent in the 'Alone' Category

Group	Mean	Median	S.D.	Min	Max	Range
IS	67.7	79.8	23.1	23.7	81.7	58
ES	38.5	39.6	19.6	18.5	58.5	40
CG	16.3	15.7	14.6	0	42.6	42.6

Difference between CG and IS, significant, $p=.0277$

Difference between CG and ES, significant, $p=.0277$

Difference between ES and IS, significant, $p=.0464$

1.2 Acknowledge

In this level of involvement the PMH subjects acknowledged the adult's presence but did not become involved in any activity or physical contact. The time spent by the PMH subjects was more evenly distributed across the three adult groups than in any other category. In particular the IS and ES groups have almost identical scores. It is possible that this level of involvement reflects the passing interest the adults stirred in the PMH subjects, whatever their actions or strategies.

Table 7.2 Percent of Time Spent in 'Acknowledge'

Group	Mean	Median	S.D.	Min	Max	Range
IS	14.3	13.7	5.4	8.9	21.6	12.8
ES	14.8	14.7	8.9	1.5	27	25.5
CG	10.5	12	7.8	0	17.5	17.5

1.3 Passive Involvement

This level of involvement indicated that the PMH subject's accepted the adult's physical intervention, but did not actively participate. The PMH subjects spent a greater amount of time in 'Passive Involvement' with the CG and ES groups compared with the IS group, but these differences were not found to be significant. Table 7.3 shows that the CG group had a very wide range of scores. One PMH subject, who responded particularly well to passive contact, accounts for much of this total. The higher percentage in the ES and CG groups compared with the IS group is interesting.

In this category the PMH subjects showed little activity, e.g. sitting shoulder-to-shoulder with the adult stroking the young person's hand occasionally. However, they were active inasmuch as they allowed the adult to be so near and to touch him. A young person who responded well to this form of communicative contact might not readily permit strangers to

approach him so closely, thus differentiating between a familiar figure and a stranger.

Table 7.3 Percent of Time Spent in 'Passive Involvement'

Group	Mean	Median	S.D.	Min	Max	Range
IS	8.1	5.6	9.8	0.1	25.8	25.7
ES	19.7	12.2	18.9	3.3	48.9	45.5
CG	24	11.2	29.8	0	71.2	71.2

1.4 Active Involvement

'Active involvement' included all communicative contact in which the PMH subject fully participated, without exhibiting the nonverbal behaviours that are usually associated with interpersonal interactions, e.g. looking at the adult. The ES group elicited the most 'active involvement', followed by the caregivers (see Table 674.)

Table 7.4 Percent of Time Spent in 'Active Involvement'

Group	Mean	Median	S.D.	Min	Max	Range
IS	4.7	0.6	7	0	15.7	15.7
ES	18.6	19	11	5.5	30.8	25.4
CG	14.6	12.5	10.5	4.5	32	27.7

Difference between CG and IS, significant, $p=.0277$

Difference between ES and IS, significant, $p=.0277$

The ES group elicited a higher amount of contact at this level with all but one PMH subject. In contrast, two of the PMH subjects did not spend any time in 'Active Involvement' with the IS group while a further two spent less than 1% of the session at this level.

A within-subjects analysis of variance showed the overall difference in amount of 'active involvement' between the three adult groups to be significant, ($X^2 (2)$, $p=.0057$). Wilcoxon tests revealed the difference to lie between the CG and IS groups and the ES and IS groups, ($p=.0277$). 'Active

Involvement’ appears to be the level of involvement at which the experience of the ES group is reflected most strongly.

1.5 Reciprocal Engagements

This level of involvement describes the fullest participation between the PMH subject and the adult. The PMH subjects were found to spend the greatest amount of time in ‘reciprocal engagements’ with their caregivers and the least with inexperienced strangers. There were no reciprocal engagements between three of the PMH subjects and IS adults. One subject spent ninety percent of his time in ‘reciprocal engagements’ with his caregiver, raising the CG percentage, but only a small percentage of time with the IS and ES groups (1% and 10% respectively). This suggests that his high level of engagement with his caregiver resulted from factors other than an easy sociability. Table 7.5 presents the summary statistics.

Table 7.5 Percent of Time spent in Reciprocal Engagements

Group	Mean	Median	S.D.	Min	Max	Range
IS	1.9	0.8	2.5	0	5.6	5.6
ES	8	3	11	0.8	29.3	28.4
CG	34.6	23.2	34.7	4.78	95.47	90.7

Difference between CG and IS, significant, $p=.0277$

Difference between CG and ES, significant, $p=.0277$

A within-subjects analysis of variance showed an overall significant difference between groups, (x^2 (2), $p=.0057$). Wilcoxon matched-pair signed-rank tests showed the significance to lie between the caregivers and both groups of strangers, but not between the IS and ES groups. The results suggest a levelling out of differences between the two groups of strangers at this deeper level of contact, with the CG’s personal knowledge of the PMH subjects yielding greater communicative advantage.

1.6 Group Profile

Table 7.6a summarises the distribution of mean percent durations for the three groups across the levels of involvement and Table 7.6b presents the significance levels of differences observed between groups.

Table 7.6a Mean percent of time spent across levels of involvement

Adult Group	Alone	Acknow	Passive Involve	Active Involve	Recip. Engage	*MC/MTO
IS	67.7	14.3	8.1	4.7	1.9	3.3
ES	38.5	14.8	19.7	18.6	8	0.4
CG	16.3	10.5	24	14.6	34.6	0

*Missed cues and missed toy offers

The communication styles of individual PMH subjects account for the surprisingly high percentage of passive involvement observed between PMH subjects and caregivers. Passive forms of contact sometimes held high communicative significance and offered the knowledgeable adult an influential communicative strategy. The next chapter, 'Individual Profiles', addresses the issue of the communicative significance of idiosyncratic responses.

Table 7.6b Significance levels of group differences

Level of Involvement	CG/ES/IS	CG vs IS	CG vs ES	ES vs IS
Alone	.01	.01	.01	.05
Acknowledge	NS	NS	NS	NS
Passive Involvement	NS	NS	NS	NS
Active Involvement	.01	.01	NS	.01
Recip. Engagements	.01	.05	.05	NS

On the evidence presented in Tables 7.6a and 7.6b it appears that the PMH subjects did discriminate between a familiar figure and strangers and that

they further discriminated between strangers who had experience in the field of mental handicap and those who did not. Both the ES and CG groups were experienced in communicating with people with profound mental handicap, suggesting that the differences observed between these two groups reflect the effects of the personal history developed between caregiver and young person. The ES group were able to use their skills to actively engage the young people, but could not achieve the deeper level of reciprocal engagements so easily. However, the results in the 'Passive Involvement' category urge caution in measuring 'more' or 'less' success solely in terms of the young person's active behaviours. Sitting quietly beside someone can be significant if the person normally shies away from closeness with others. Thus, the caregivers' personal knowledge and the expertise of the ES group are also reflected in their recognition of and response to the individual young person's needs.

1.6 Initiation and Rejection

The number of times the young people 'initiated and rejected' contact was also calculated to gain an impression of how much of their involvement was prompted by the adult and whether there was resistance to involvement, especially with strangers.

1.6.1 Initiation of all events

Within a total of 1,220 observations, i.e. all observations excluding solitary activity, the PMH subjects initiated events¹ on 222 occasions (18% of the observations). Overall the subjects initiated more frequently with their caregivers, followed by the experienced strangers, but the individual picture is more informative as shown in Table 7.7. 'Missed cues' and 'missed toy offers' are also included.

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¹Individually coded items as opposed to episodes of reciprocal engagements.

Table 7.7 Number of events initiated by each PMH subject

PMH Subject	IS	ES	CG
Michael	0 [2MC/2MTO]	3 [1MC]	22
Philip	2	12 [6MC]	6
Mary	1 [3MC]	6	0
Robert	0	16	25
Sean	29 [4MC]	22 [1MC]	34
Terry	21 [8MC]	21	2
Total	53 [17MC/2MTO]	80 [8MC]	89

The 'missed cues' and 'missed toy offers' usually generally lasted several seconds. However, Terry's physical cues to persuade two of the IS adults to walk round the room with him were longer, lasting around eighteen seconds. He was attempting to guide the adult into moving backwards so that he could walk forwards facing the adult and, although his prompt seemed clear to the experienced eye, both adults reported that they had been unaware of his prompts. The number of missed cues was small and descriptive accounts² may be more informative than frequencies.

1.6.2 Initiation of Reciprocal Engagements

Episodes of reciprocal engagements initiated by the PMH subjects provide possibly the clearest visible evidence of a young person's wish to be fully involved with another person. When their individual patterns are studied it is seen that four of the subjects initiated reciprocal engagements (see Table 7.8). For three subjects this amounted to a small percentage of their engagements, but a fourth subject initiated over half of his engagements. Two subjects initiated brief engagements with the ES group, and one subject with the IS group.

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² See example in Mary's individual profile in Chapter 7.

Table 7.8 Mean percent of Reciprocal Engagements initiated by PMH subjects

Subject	IS	ES	CG
Michael	0	0.33	54.50
Philip	0	0	0
Mary	0	0	0
Robert	0	0.84	2.76
Sean	0	0	1.24
Terry	0.25	0	4.4

Michael was a difficult communication partner for all strangers, whether they had experience in mental handicap or not. He was very lively and enjoyed social contact, but it was very difficult to understand the meaning of his actions and responses without some personal knowledge of his idiosyncrasies. In communication episodes with a known person he was a fully participating and influential partner, but it would be very easy for those who did not know Michael to underestimate his capability and desire for communication.

1.6.3 Rejection of contact

The PMH subjects were more likely to ignore the adults than to actively reject intervention, i.e. they simply did not permit involvement in the first place. None of the adults attempted to force the young people to do anything against their will and rejection arose when an adult inadvertently transgressed boundaries, e.g. moving too near a subject for his/her comfort, encouraging a further response after the young person had lost interest in an event. Therefore the low number of rejections does not necessarily suggest a willingness to be with adults at all other times, as the amount of time spent in solitary activity confirms. The distribution of rejection across the PMH subjects is shown in Table 7.9.

Table 7.9. Total Number of Rejections of Contact across four sessions per Adult Group

PMH Subject	IS	ES	CG
Michael	0	0	0
Philip	5	8	0
Mary	2	4	1
Robert	2	0	1
Sean	3	0	0
Terry	2	0	0
Total	14	11	2

1.7 Individual Differences

Tables 7.7-7.9 show that the PMH subjects did not all follow the same pattern of initiation and rejection and, in section 1.3, individual modes of communication were reported to account for the CG's surprisingly high level of 'passive involvement'. These examples illustrate that information about individuals needs to be studied in conjunction with group patterns. Individual differences both create and explain anomalies observed in the group profile, as demonstrated cogently in observations of the extreme ends of shared involvement: 'self-absorbed behaviour' and 'reciprocal engagements'.

The majority of observations in the 'Solitary Activity' category of the Shared Involvement schedule were coded 'self-absorbed'. This event denoted no contact of any kind between the adult subject and PMH subject. Although most adults focused their attention on the PMH subject during these periods, attempting to gain his or her attention, the young person paid no attention in any way to the adult.

This event provides a clear picture of 'separateness': there are no observable signs in the PMH subject's behaviours that an adult is present in the room, there is no touching by the adult in any form, including adjusting the PMH

subject's position. The distribution of the self-absorbed behaviour of the PMH subjects across the three groups is shown in Figure 6.1.

Figure 7.1 PMH Group: Self-Absorbed Behaviour

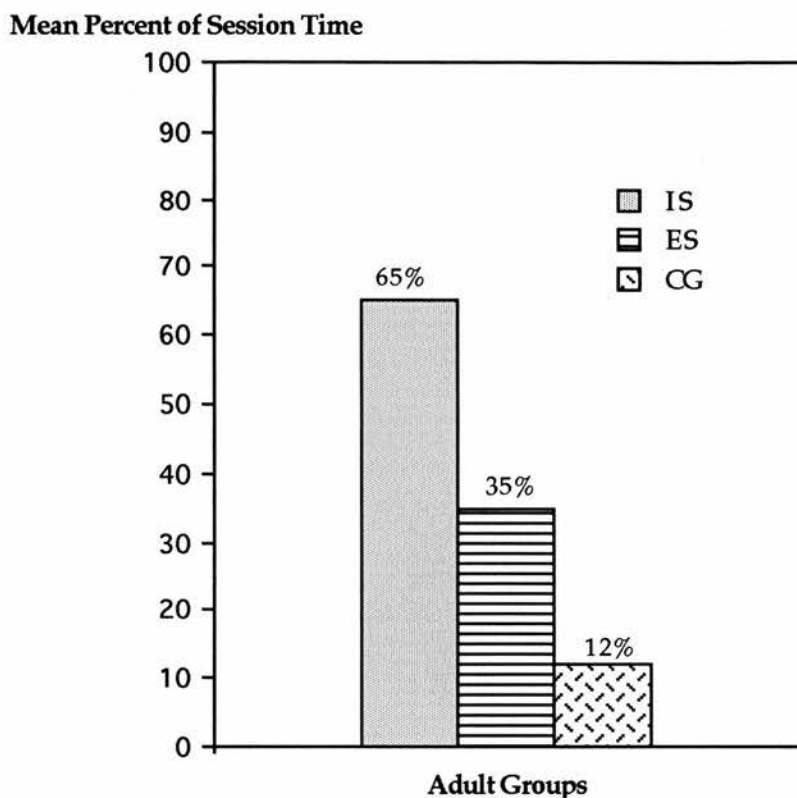
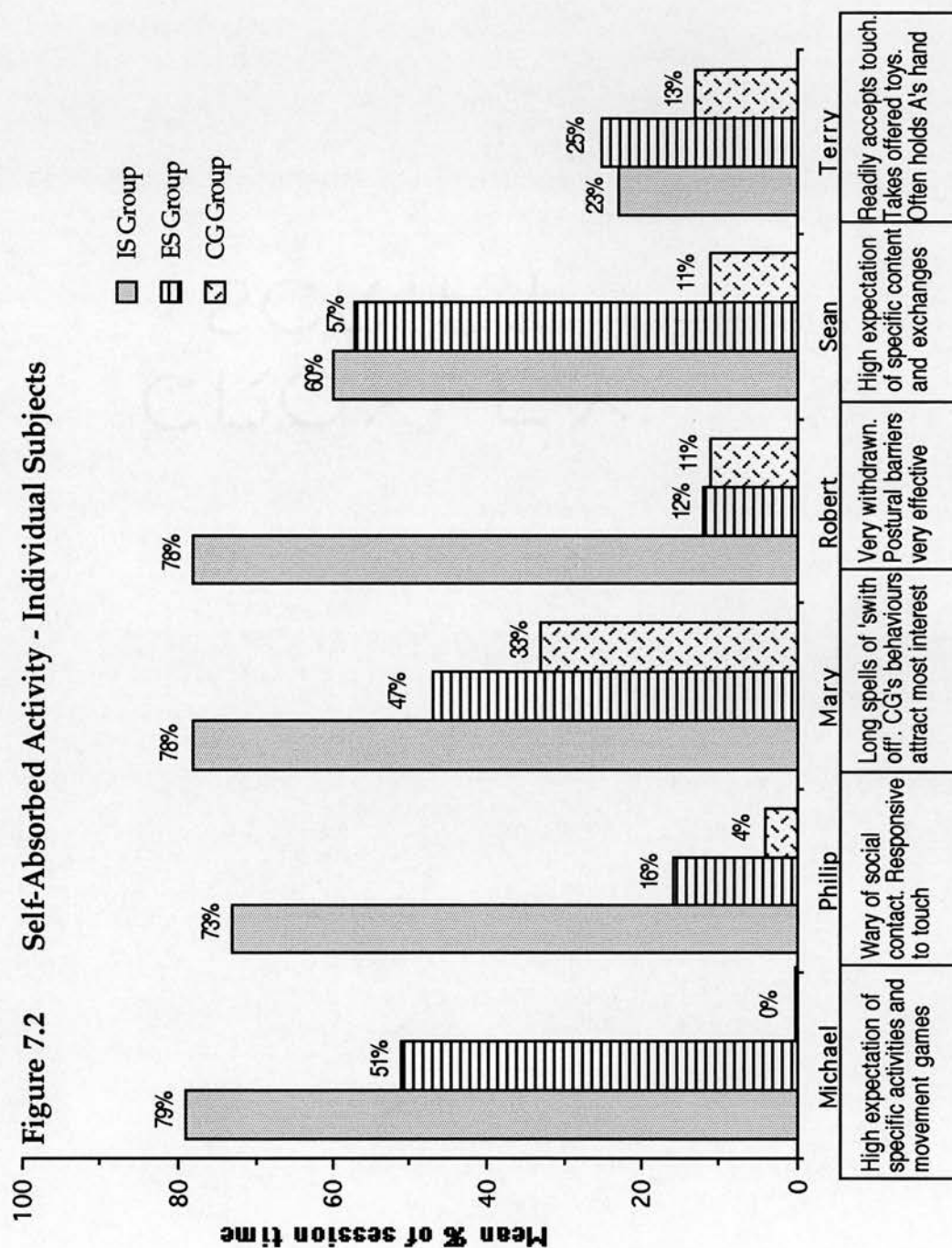


Figure 7.1 shows the clear difference in the impact made by the IS, ES and CG groups on the PMH subjects' self-absorbed behaviour. However, the pattern of distribution is not the same for each PMH subject, as Figure 7.2 shows overleaf.

There were large variations in the ways and extent to which the young people communicated and in the impact caused by the familiarity of the adult. The experienced strangers found their previous experience particularly helpful with Philip and Robert, the two withdrawn subjects, and least helpful with Michael and Sean, the two who behaved in a difficult way with those unknown to them.

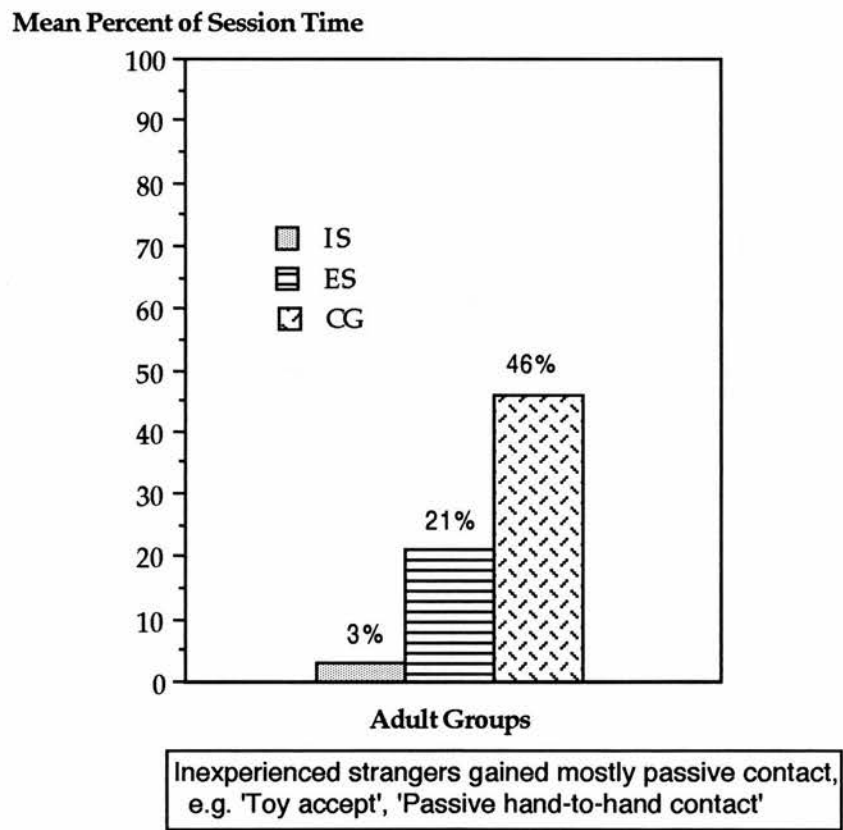
Figure 7.2 Self-Absorbed Activity - Individual Subjects



Michael and Sean had specific expectations of how an adult partner should respond and the sorts of exchanges they should have with the adult and when these expectations were not met they switched their attention away. In particular, Michael expected to play and communicate in very specific ways. He was lively, able to interact well and liked lots of physical games, having a large repertoire of activities he enjoyed. Any stranger was at a disadvantage in not possessing knowledge of what he preferred to do.

Terry and Mary, who were generally sociable and responded as far as they were able, were found to be the easiest to cope with by all strangers, with less of a difference being found between the amount of contact achieved by caregivers and strangers. In fact, the IS group appears to have fared better with Terry than the ES group. However, when Terry's individual profile is studied in yet more detail a different picture emerges, as seen in Figure 7.3.

Figure 7.3 Terry - Mutual Involvement (Toy)



Most of Terry's involvement with the IS group is at a superficial level, e.g. passive hand-holding, but once his interest is captured he will readily engage in mutual play with toys, this form of contact accounting for most of his reciprocal engagements. The ES group had greater success in encouraging this deeper level of involvement than the inexperienced group.

Similar differences were noted for 'Reciprocal Engagements', the deepest level of involvement. The overall distribution between the adult groups is shown in Figure 7.4, while Figure 7.5 shows that this distribution was not noted across all six PMH subjects.

Figure 7.4 PMH Group: Reciprocal Engagements

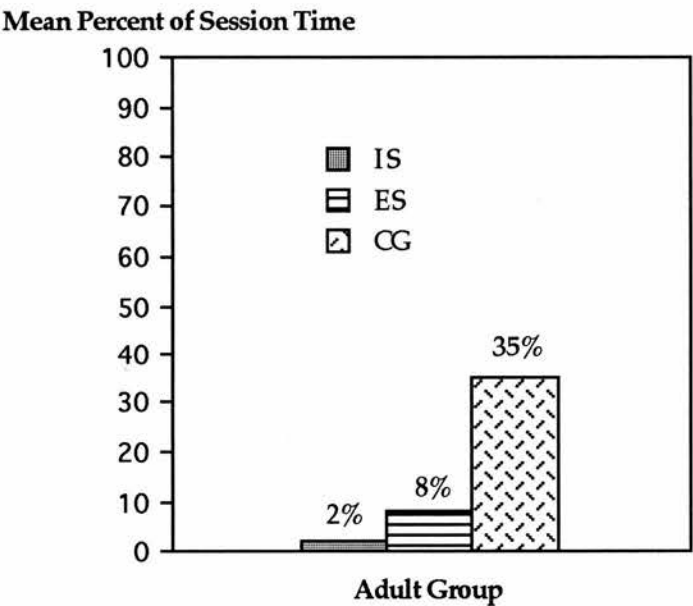
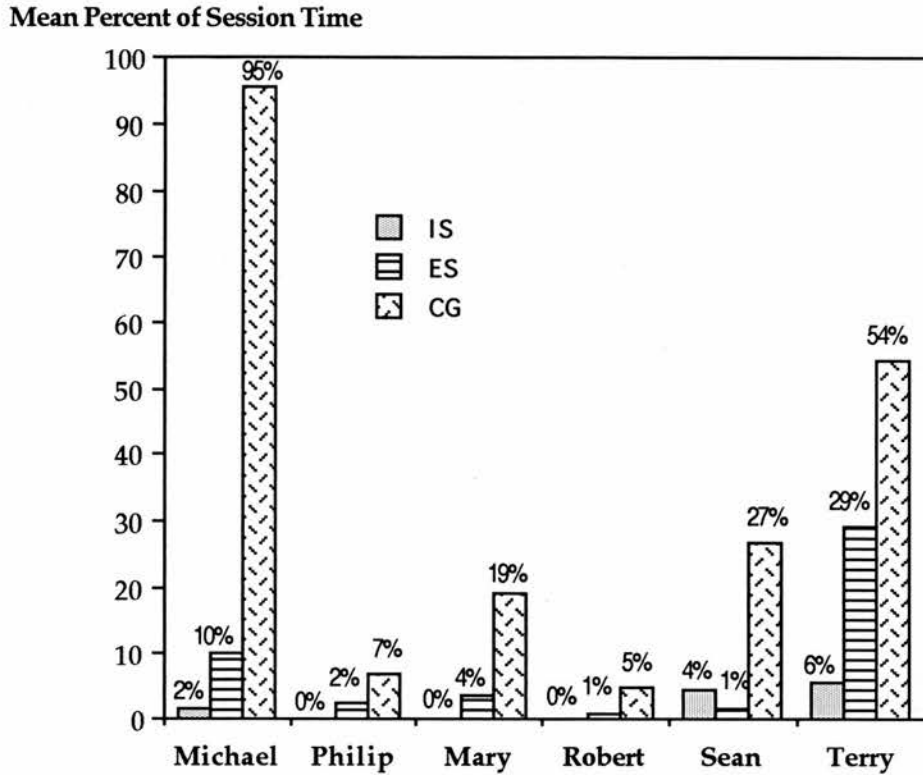


Figure 7.5 Reciprocal Engagements: PMH Subjects



Clearly it is helpful to have information about individuals as well as the group in evaluating the differences the experience of the adult subjects might have on the PMH subject's involvement. Yet the individual responses also need to be interpreted with caution. Mary and Robert had the same caregiver, but it should not be assumed that she did less well with Robert than Mary. She elicited less reciprocal contact with Robert, but he did not respond so readily to social overtures as Mary, and his responses are more usually through physical contact than more conventional nonverbal communication.

Individual profiles are presented in detail in Chapter 8.

2. CAREGIVER REVIEWS

The caregiver reviews had two purposes: 1) to find out if judgements based on personal knowledge of the young people would resemble the patterns revealed by the 'Shared Involvement' analysis, and 2) to gather anecdotal evidence accumulated from the caregivers' personal relationships with the young people.

2.1 Review 1

The caregivers' judgements were in broad agreement with the main analysis: they considered the two groups of strangers had more difficulty in gaining some form of communicative contact with the PMH subjects than they did, with the IS group having the greatest difficulty. Although there is a possibility that the caregivers' judgements were biased in favour of themselves, this did not appear to be the case. During the reviews they acknowledged appreciatively any episodes with both groups of strangers where the young person participated particularly well. Sessions where there was little response were viewed sympathetically, often with remarks such as "well, it's difficult when you don't know them." The caregivers focused their attention on the young person rather than the adult, praising them for their responses and empathising with the young person's actions. Often, when there was little response, a caregiver would spur the young person on, e.g. "come on, lift your head up, give him a smile." Therefore, it seems more likely that any bias was towards crediting the young people with responses, rather than failing to acknowledge their responses to a particular group of adults.

The caregivers identified a pattern of group differences which showed similarities with the Shared Involvement analysis. They judged the PMH subjects to show the greatest awareness of the adult's presence when with caregivers and the least awareness when with the IS group. The percentage of time during which the PMH subjects showed awareness towards the adult groups is shown in Table 7.10.

Table 7.10 Percentage of Time Spent showing Awareness of Adult

Group	Mean	Median	S.D.	Min	Max	Range
IS	32.1	20.4	26	7.3	74.4	67.1
ES	57.9	56.7	21.2	25.7	85.5	59.8
CG	85.4	95.4	23.7	37.8	100	62.2

Difference between CG and IS, significant, $p=.0277$

Difference between CG and ES, significant at $p=.0277$

Difference between ES and IS, NS

A Friedman within-subjects analysis of variance showed an overall significant difference between groups, ($X^2 (2), p=.0057$). Wilcoxon matched-pair signed-rank tests between the individual groups showed a significant difference between the caregivers and both groups of strangers, ($p=.0277$). Although the ES group produced a greater percentage of awareness compared with the IS group, this difference was found to be not significant.

The caregivers were asked to make coarse-grained subjective judgements of moments when the PMH subject showed any sign of awareness of the adult, in contrast to the finer grain analysis of the Shared Involvement analysis. For example, a caregiver might rate a five-minute section of tape as 'aware' because of physical contact between the young person and the adult while, for the same segment, the main analysis recorded different forms of physical contact, mostly initiated by the young person, interspersed with several seconds of solitary activity. In the coding schedule, the onset and offset of events were precisely defined, with the start of an event taken from the very beginning of the action, e.g. the first frame in which the young person was seen to turn his head. In the caregiver reviews the tape was stopped when requested by the caregiver and the time counter noted, although a caregiver did sometimes pinpoint precise brief moments as meaningful.

Consequently, the caregivers' judgements of 'awareness' are not directly comparable with any of the levels of shared involvement. Nevertheless, some comparison is possible between the percentage of time in which the caregivers judged there to be no involvement between young person and adult and the Solitary Activity category. Table 7.11 compares the percentage of time the PMH subjects spent 'uninvolved' with the amount of Solitary Activity, and shows close agreement, especially in the IS group.

Table 7.11 Amount of time when PMH subjects uninvolved

Group	Mean	Median	S.D.	Min	Max	Range
IS	*67.9	79.6	26	25.6	92.7	67.1
	67.7	79.8	23.1	23.7	81.7	58
ES	41.9	43.3	20.9	14.5	73.3	58.8
	38.5	39.6	19.6	18.5	58.5	40
CG	14.6	4.6	23.7	0	62.2	62.2
	16.3	15.7	14.6	0	42.6	42.6

*CG's judgements on upper line in bold
Solitary Activity on lower line

It can be seen that there is agreement between the caregivers' observations and the main analysis on three points: 1) the amount of time in which nothing at all was happening between the PMH subjects and adults, 2) the amount of time in which the PMH subjects showed an awareness of the adults and, 3) the direction of the differences observed between the three groups of adults.

2.2 Review 2

During the second reviews with fifty per cent of the recordings, the caregivers judged the amount of time spent by the PMH subjects in three exclusive levels of involvement³ - 'Aware', 'Involved' and 'Very Involved' - when with the three adult groups. The second reviews revealed a

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³The three levels were the same as those used in Study 1:

Aware: The child is a spectator. He/she shows awareness of his/her mother or gives her some attention, but does not get involved in what she is doing.

Involved: The child is a passive participant. He/she responds to what his/her mother is doing with actions and sounds, e.g. smiles, vocalisations, reaching out, turning head towards mother.

Very Involved: The child is an active participant. He/she not only responds to the mother, but plays a part in keeping the interaction going, or initiates contact.

hierarchical order of involvement which resembled the findings of the main analysis.

The percentage durations for the three levels of involvement are presented in Tables 7.12a, 7.12b and 7.12c.

Table 7.12a Percentage of Time Spent in ‘Awareness’

Group	Mean	Median	S.D.	Min	Max	Range
IS	21.3	16.8	15.8	7.3	50	42.7
ES	23.2	21.5	12.4	8.7	45.9	37.1
CG	23.6	6.9	36.8	0	93.6	93.6

Clearly, there was little difference seen in the amount of time spent in this level of contact. The results for ‘awareness’ bear some similarity with *Acknowledge* and show a similar distribution across the three groups.

Table 7.12b Percentage of Time Spent in ‘Involved’

Group	Mean	Median	S.D.	Min	Max	Range
IS	4.8	4.6	5.1	0	11.7	11.7
ES	18.7	17.6	11.5	3	32	29
CG	29.3	17.7	34.7	0	89.9	89.9

Although the observed trend between the three groups is in accordance with all other findings in the study, a within-subjects analysis of variance yielded no significant differences in the amount of time the PMH subjects spent ‘involved’ with the three adult groups.

Table 7.12c Percentage of Time Spent in ‘Very Involved’

Group	Mean	Median	S.D.	Min	Max	Range
IS	0.9	0	2.2	0	5.4	5.4
ES	5.8	2.1	8	0	19.4	19.4
CG	30.6	6.9	42.3	0	100	100

Only one PMH subject spent time in 'very involved' with the IS group, three subjects spent time in this category of involvement with the ES group and five with the CG group. The CG percentage is raised by one subject, Michael, who had a similar effect on the 'Reciprocal Engagement' scores.

Review 2 used a smaller, randomly selected sample of recordings, but representative of each individual's communicative responses. Tables 7.12a-c show that the CG's achieved more involvement (in amount and depth) than the two groups of strangers and that the ES group were also successful in gaining the young person's involvement. In keeping with all other results, the IS group were the least successful.

The second reviews were perhaps most valuable in the descriptive information obtained from the caregivers. This contributed information to the individual profiles of the PMH subjects that would not have been revealed by the coding schedule. These descriptions are incorporated in the individual profiles presented in the next chapter.

3. PHYSICAL CONTACT

There were wide variations in how the PMH subjects responded to and used physical contact: forms of contact which held significance for one PMH subject might be an everyday occurrence for another. Caregivers and experienced strangers were observed to use many active contact movements (e.g. patting), to elicit and maintain responses, using active contact more widely than other forms of physical contact. Many of these movements were action cycles, which are described in the Chapter 9. Physical contact was studied as a product of the dyad and calculations included the contact initiated by both the adult subject and PMH subject. The pattern of contact for each PMH subject, as a recipient and initiator, was examined in each of his/her twelve recording sessions across the three groups of adults.

The Physical Contact category contained 29 codes to accommodate its permutations and the onset and offset of all occurrences of physical contact were noted. Table 6.13 summarises the different forms of contact and the pattern of use observed within the IS, ES and CG groups. Abbreviations for each description are displayed in brackets and are used in Table 7.14.

Table 7.13 shows that all adult groups used passive hand-holding, passive and active touching, and also used physical cues and prompts to encourage the PMH subjects' participation. It can also be seen that the PMH subjects initiated hand-holding and hand games and physically led the adult round the room when with each group of adults. However, the table also shows that there was a greater variety in the forms of touching used by the ES and CG groups compared with the IS group. When the cumulative amounts of time the PMH subjects and adult subjects spent in each form of contact is shown, the contrast between the IS group and the other two groups becomes more marked.

Table 7.14 reveals that the majority of the IS group's physical contact is passive hand-holding initiated by the adult and the PMH subject (the percentage of the group total is given in brackets).

Table 7.13 Different Forms of Physical Contact used by Adult Groups

Forms of Physical Contact	IS	ES	CG
A. rests hand on YP's body (HBMR)	YES	YES	YES
A. holds YP's hand (HHMR)	YES	YES	YES
A. and YP rest against each other's bodies (BCMR)	YES	YES	YES
A. jiggles, pats YP's limbs and body (HBAA)	YES	YES	YES
A. pats, strokes and plays with YP's hand (HHAA)	YES	YES	YES
A. jiggles, bounces, rocks YP (BCAA)	No	YES	YES
A's hand rests against YP. YP physically active (HBSA)	No	YES	No
A. holds YP's hand, YP is physically active (HHSA)	No	No	YES
Hand-body contact A. and YP are both active (HBBA)	No	YES	YES
Hand games in which both A and YP are active (HG)	No	YES	YES
Body contact in which both A and YP are active (BCBA)	No	No	YES
YP rests hand on A's body (IHBMR)	No	YES	YES
YP initiates passive hand holding (IHHMR)	YES	YES	YES
YP initiates body contact. YP and A. rest against each other (IBCMR)	No	YES	YES
YP rests hand on A's body, A. physically active (IHBAA)	No	No	YES
YP holds A's hand while A. is active (IHHAA)	YES	YES	YES
YP initiates body contact, A bounces, jiggles etc. (IBCAA)	No	YES	YES
YP plays with A's hand. A. remains inactive (IHHSA)	No	YES	YES
YP places hand on A's body, both active (IHBBA)	No	No	YES
YP initiates active hand games with A. (IHG)	YES	YES	YES
YP initiates body contact. YP and A. are active (IBCBA)	No	YES	YES
Adult leads YP round room (LA)	YES	No	YES
YP leads adult round room (LS)	YES	YES	YES
A. & YP walk together in physical contact (LB)	No	No	YES
A. uses physical cues to encourage YP's participation (SPE)	YES	YES	YES
Hand holding to physically support movement activities (ACTA)	No	YES	YES
Hand holding initiated by YP to physically support movement activities (ACTS)	YES	No	YES
Hand holding to physically support movement activities in which the YP is active (ACTAB)	No	YES	YES
Hand holding initiated by the YP to physically support movement activities in which he/she is active (ACTSM)	No	YES	YES

Table 7.14 Mean totals of physical contact (in seconds)

Phy. Cont	IS	ES	CG
HBMR	8.8 (3)	21.6 (3)	15.97 (2)
<i>HHMR</i>	112.88 (43)	96.2 (16)	59.75 (6)
BCMR	6.2 (2)	65.6 (11)	122.85 (13)
HBAA	10.08 (4)	60.8 (10)	154.85 (16)
HHAA	9.17 (3)	96.38 (16)	119.87 (13)
BCAA	*	29.43 (5)	103.8 (11)
HBSA	*	4.6 (1)	*
HHSA	*	*	3.3 (0.3)
HBBA	*	6.88 (1)	8.05 (1)
HG	*	1.4 (0.2)	6.65 (1)
BCBA	*	*	21.07 (2)
IHBMR	*	6.72 (1)	5.32 (1)
<i>IHHMR</i>	72.17 (28)	76.32 (12)	47.25 (5)
IBCMR	*	23.85 (4)	1.52 (0.2)
IHBAA	*	*	11.05 (1)
IHHAA	5.97 (2)	54.9 (9)	49.05 (5)
IBCAA	*	19.3 (3)	40.4 (4)
IHHSA	*	2.47 (0.4)	5.43 (1)
IHBBA	*	*	29.02 (3)
IHG	1.25 (0.5)	4.83 (1)	16.15 (2)
IBCBA	*	2.47 (0.4)	5.43 (1)
LA	7.06 (3)	*	3.05 (0.3)
LS	17.27 (7)	4.65 (1)	19.7 (2)
LB	*	*	5.83 (1)
SPE	6 (2)	4.27 (1)	1.97 (0.2)
ACTA	*	7.22 (1)	8.27 (1)
ACTS	3.48 (1)	*	36.48 (4)
ACTAB	*	15.23 (2)	18.6 (2)
ACTSM	*	10.03 (2)	5.73 (1)

*denotes no observations

Passive hand holding codes displayed in Italics.

% above '1' rounded to nearest whole number

Table 7.15 displays the mean total amount of physical contact observed across the three adult groups.

Table 7.15 Mean total physical contact (in seconds).

Group	Mean	Median	S.D.	Min	Max	Range
IS	260.3	149	331	10.2	917.4	907.2
ES	615.7	439.7	448.2	233.9	1306.4	1072.5
CG	936.1	1004.3	562.5	294.8	1729.5	1434.7

A Friedman within-subjects analysis of variance failed to reach significance, yet Tables 7.13 and 7.14 show marked differences in quantity and distribution between the IS and the other two groups. When the range of scores in each group is examined it can be seen that hand holding accounts for 71 per cent of all physical contact in the IS group, while there is a wider variance in the other two groups. The large amount of hand-holding distorts the picture and when it is excluded from the analysis a more representative pattern is obtained (see Table 7.16).

Table 7.16 Mean amount of physical contact ,excluding passive hand-hold

Group	Mean	Median	S.D.	Min	Max	Range
IS	75.3	63.7	61.4	8	183.8	175.8
ES	452.6	272.5	417.1	105.3	1190.4	1085.1
CG	829.1	852.8	524.6	283	1576.9	852.8

Difference between CG and IS, significant, $p=.0277$

Difference between Cg and ES, NS

Difference between ES and IS, significant, $p=.0277$

An analysis of variance on this data yields an overall significance, (χ^2 (2), $p=.0094$). Wilcoxon tests showed that this significance lay entirely between

the IS group and the other two groups, ($p=.0277$). The difference between the ES and CG groups was not significant. The large standard deviations and wide ranges of the ES and CG groups are indicative of the fluctuations in their response to individual young people. The IS group appears to be giving a blanket response to all the PMH subjects, whereas the ES and CG groups appear to be driven by the specific young person's needs and responses.

Figures 7.6 and 7.7 show the amount of physical contact observed with each PMH subject (combined amount of touching by adults and PMH subjects). Figure 7.6 includes hand-holding and Figure 7.7 excludes this form of contact. Apart from Terry, who elicited much of the IS group's hand-holding, the pattern of distribution is similar in both figures.

In the UK we would not normally expect to see so much touching between adults and young people of this chronological age, or between a family member and young person in public. In fact, we would not expect to see this amount of physical contact between any two people within minutes of meeting each other for the first time. The ES and CG groups markedly transgressed the conventional (UK) cultural rules governing physical contact.

It could be argued that the ES adults, less inhibited by the young person, were merely displaying their own individual styles rather than being driven by the subject. However, the observations showed the experienced strangers not only used more physical contact with individuals who respond best to a physical approach, but also tailored it in a similar way to the PMH subject's caregiver.

It is also interesting that the two caregivers who were paired with two PMH subjects showed differences in their use of physical contact with each subject. This suggests that it is indeed the young person's needs which are shaping the adult's form of physical contact.

Figure 7.6 Physical Contact (incl. hand-hold)

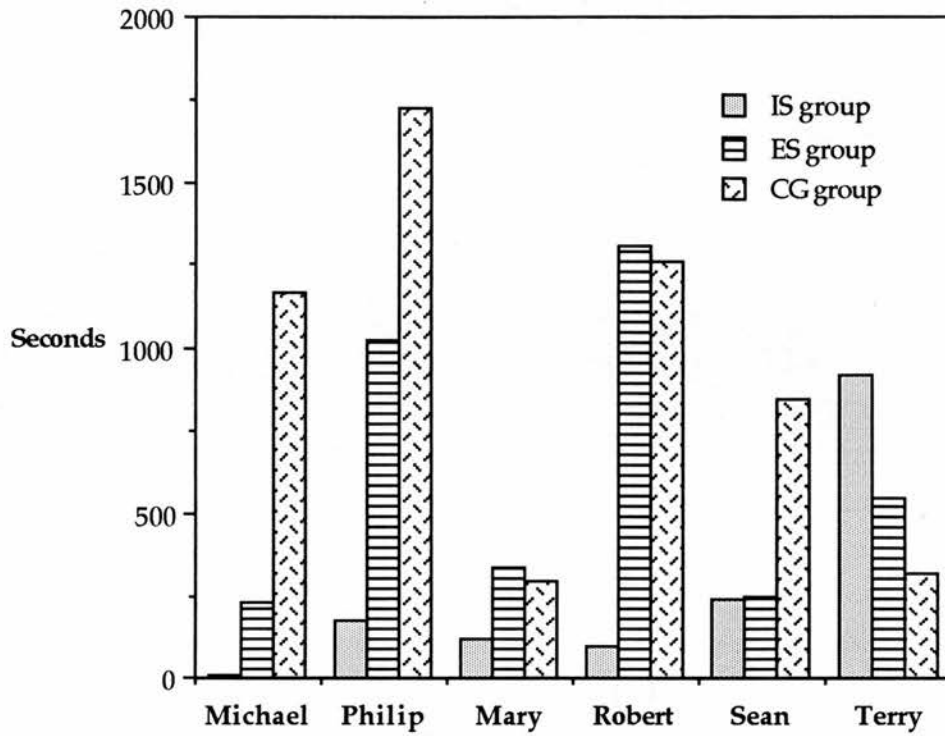
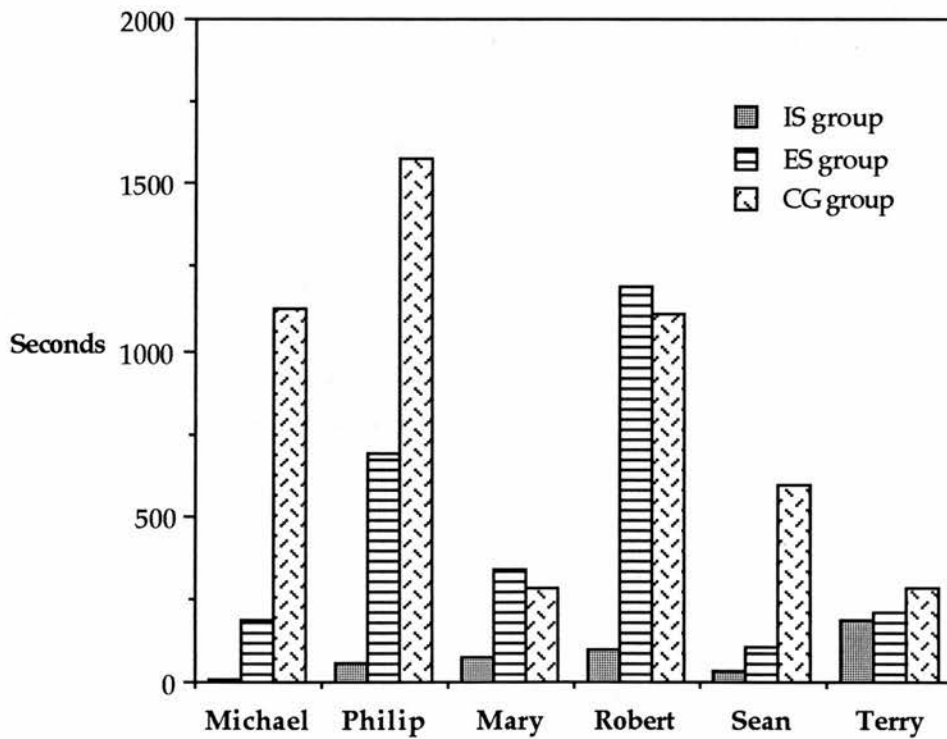


Figure 7.7 Physical Contact (excl. hand-hold)



Figures 7.6 and 7.7 showed that the amount of contact differed between the individual PMH subjects.

Figures 7.8 - 7.13 show that the forms of contact also differ between individuals, e.g. Philip's profile suggests that physical contact plays a more extensive role in his communication than it does for Mary.

Figures 7.8 - 7.13 are presented to illustrate the patterns of contact rather than specific details. The numbers at the top, along the X-axis, correspond to the sequence of physical contact categories presented in Tables 7.13 and 7.14, e.g. 1 = adult rests hand on young person's body (HBMR).

Figure 7.8

Michael

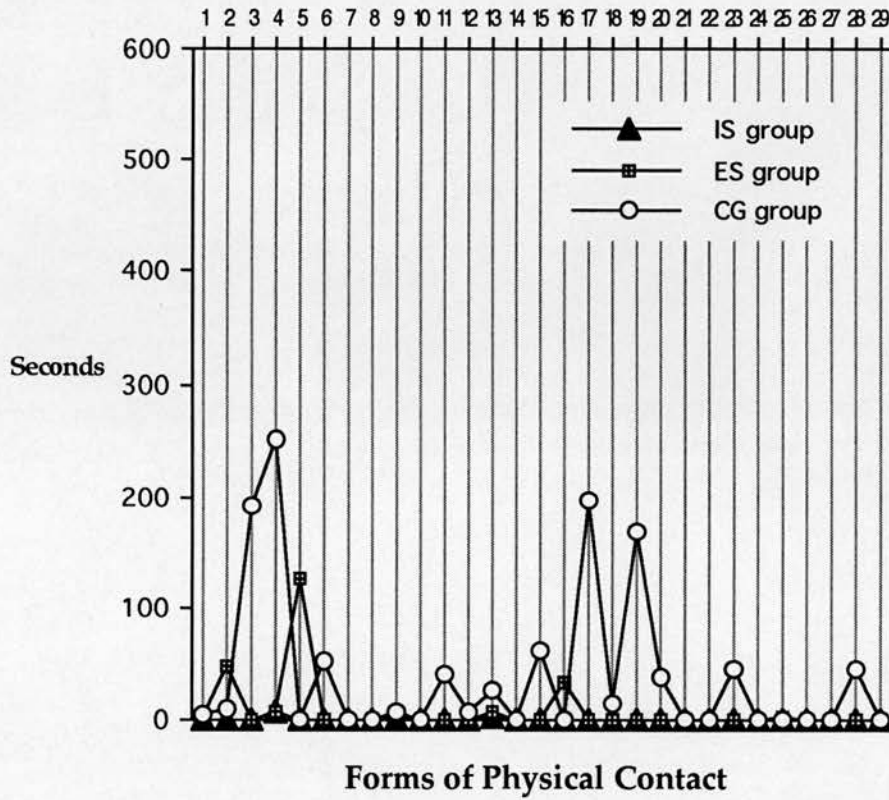


Figure 7.9

Philip

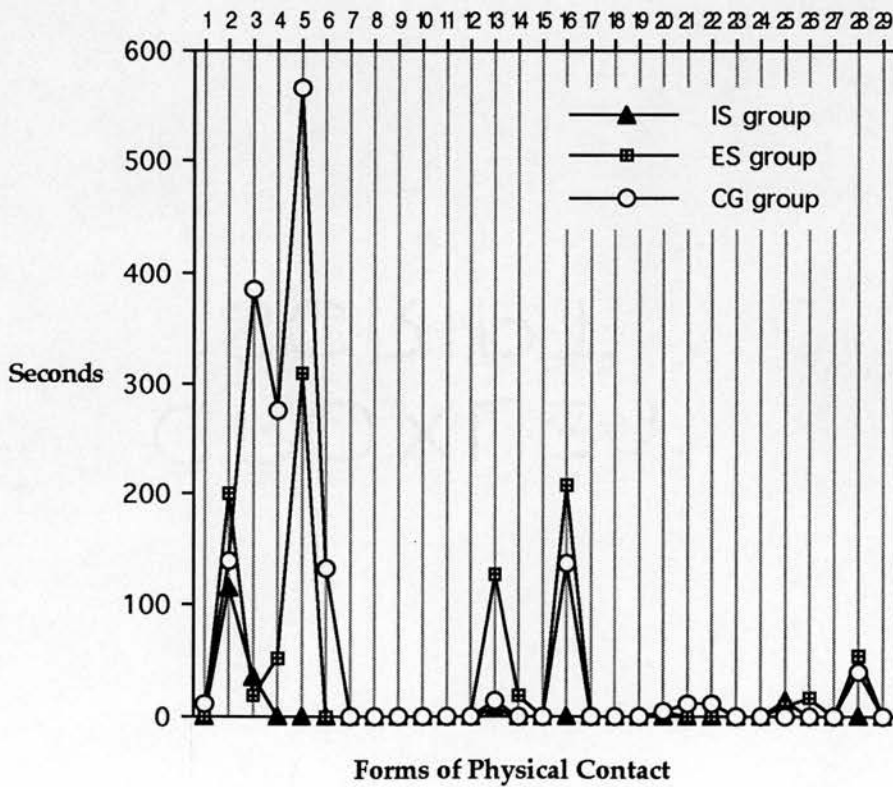


Figure 7.10

Mary

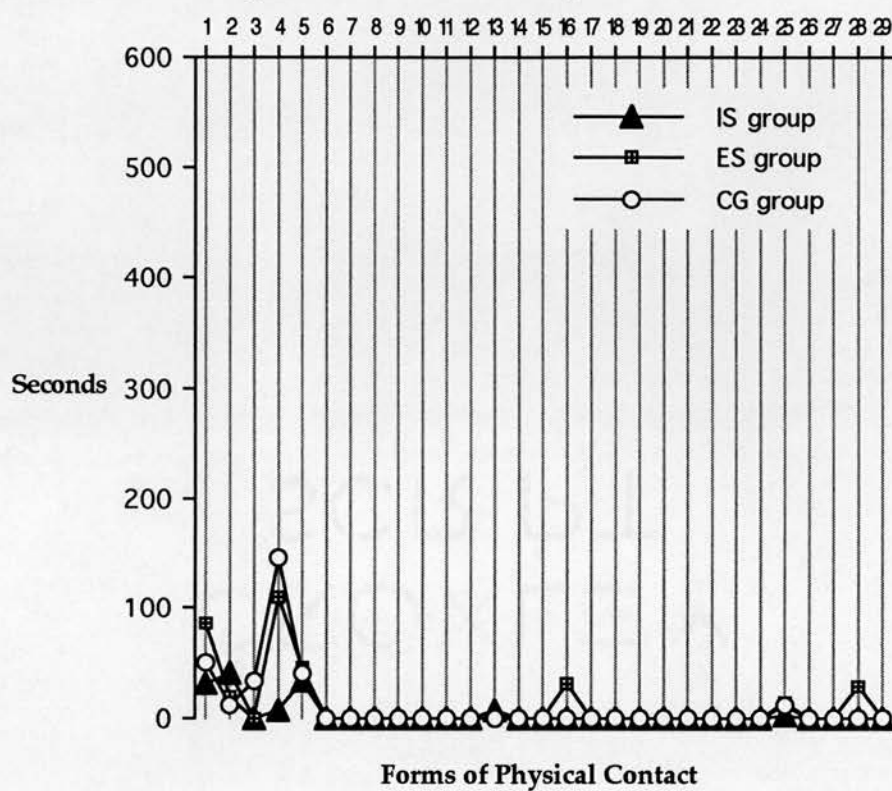


Figure 7.11

Robert

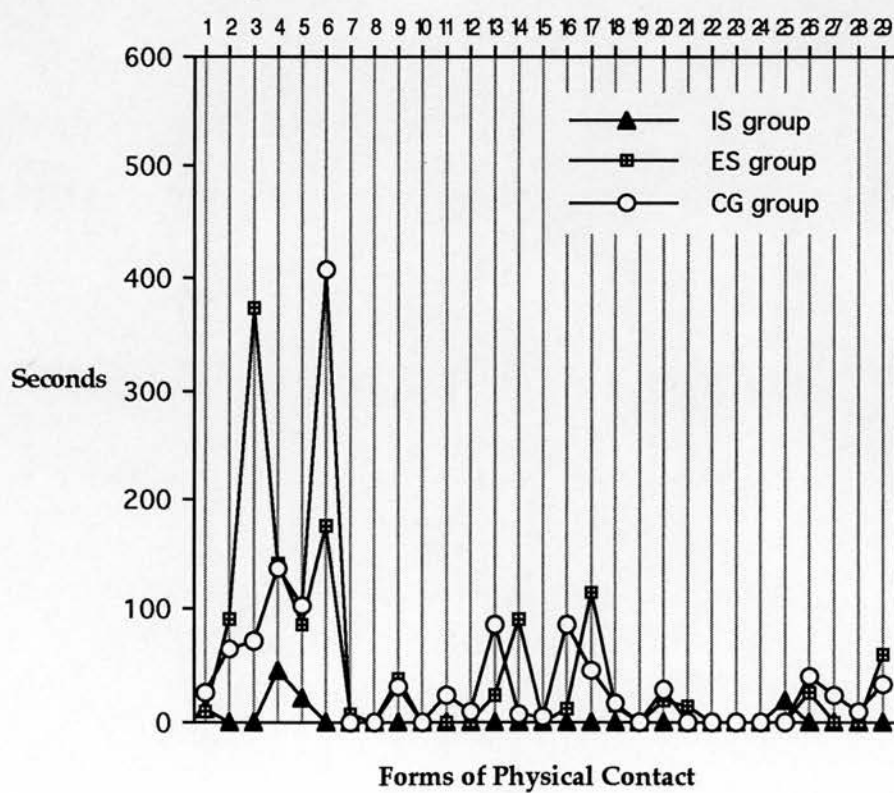


Figure 7.12 Sean

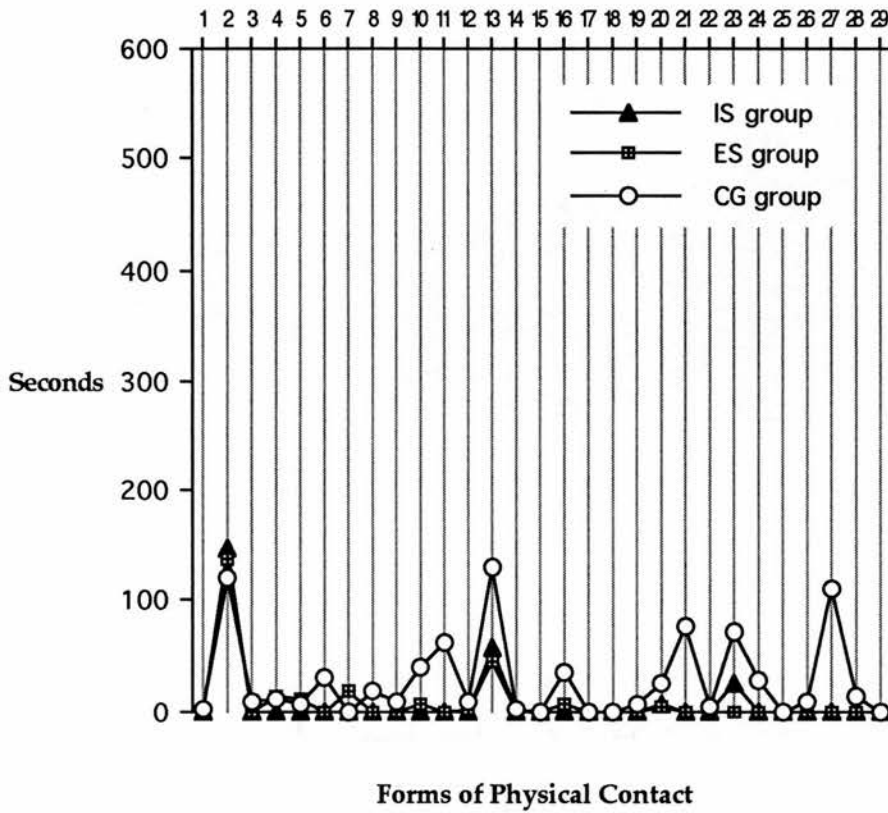
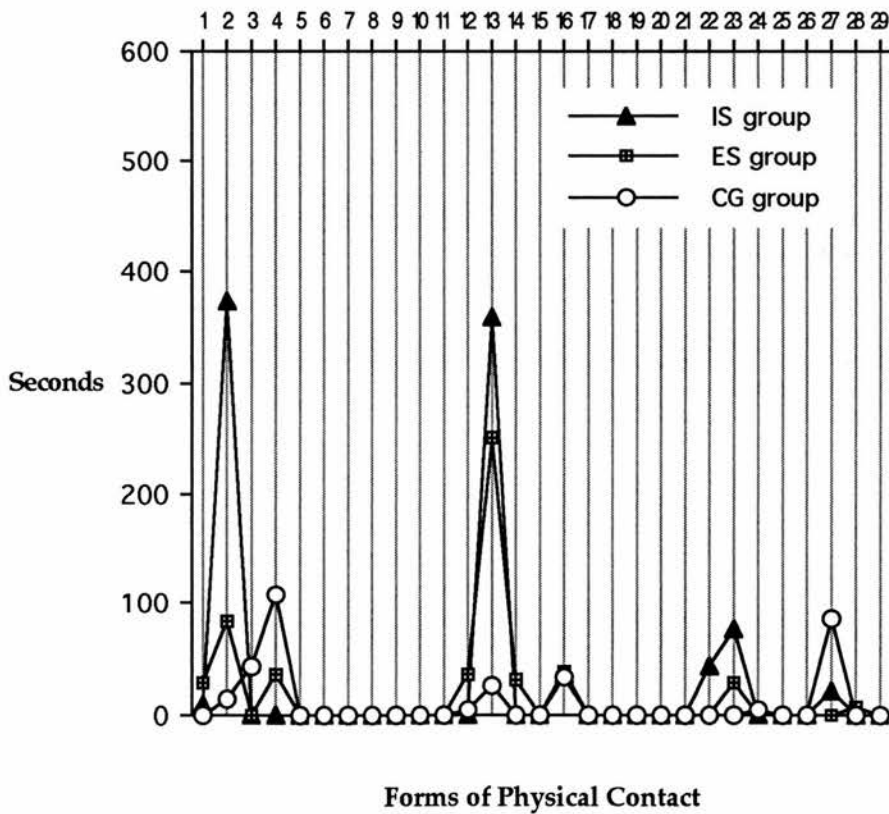


Figure 7.13 Terry



The caregivers were observed to generate the greatest amount of physical contact. However, the distribution patterns for individual PMH subjects show that the caregivers did not generate the most contact with each subject, but that they did create highly individual patterns.

Many of the experienced group of strangers reported that they exerted caution until they had some idea of the young person's tolerance of being touched. They were aware that physical contact was important, but that there were many individual preferences and degrees of tolerance. Some adults reported that they held back until they felt more certain of the kind of touching that would be acceptable to the young person, but that they themselves did not feel uncomfortable about using touch. On the other hand, most of the IS group reported a feeling of personal discomfort in touching and being close to adolescents and young adults. Holding the young person's hand was the form of physical contact they used most, as opposed to the more active contact movements. Some inexperienced strangers reported that they had wondered if touching would help to open up some communication, but did not know what to do and if this would be permissible. They would not have felt the same doubts with children. Nevertheless, the IS group did use physical contact with the PMH subjects more often than would be expected with non-handicapped young people.

These results suggest that physical contact does have an important role to play in communication with people with profound mental handicap, but it is not employed in the same ways and to the same extent with all individuals. The needs and preferences of the young person with profound mental handicap shapes the amount and form of physical contact that an adult partner might give.

CHAPTER 8: STUDY 2

INDIVIDUAL PROFILES

Each young person's profile of involvement is presented in this chapter, incorporating descriptive information obtained from the caregiver's second review.

1. COMMUNICATIVE SIGNIFICANCE

Statistical versus Descriptive Information

Statistical analyses demonstrated that the observed differences in the amount of solitary activity and interpersonal contact exhibited by the PMH subjects when with the three adult groups were unlikely to have occurred by chance and made it possible to show where the significant differences between the groups lay. However, as Plutchik (1968) states, statistical results do not reveal the whole picture: statistical significance and communicative significance are not synonymous. Philip, who found social contact stressful, provides a good example. He did not respond readily to social overtures and became anxious if people moved too close or attempted physical contact too quickly. However, his principal means of interpersonal contact was through physical contact - the very thing he found most difficult. He indicated acceptance of, and a response to, the other person by allowing him or her to remain near him. It was a major form of acceptance if he permitted physical contact, perhaps with the adult resting a hand on his arm. When Philip allowed someone to maintain physical contact in an active way, e.g. patting or stroking his hand, it was a very significant event.

Information about individuals is lost when behaviours are codified for statistical analysis of group parameters. Yet it is often descriptive information which is the most helpful in revealing the most effective ways of encouraging communication in people with profound mental handicap. Statistics cannot guarantee meaningful conclusions and research findings need to be evaluated through sources of information as well as statistical tests (Plutchik 1968). Robson (1973) makes the point that in everyday terms 'significant' means 'important', but that in statistical tests it simply

means that something is unlikely to have happened by chance. It says nothing about the practical importance of the effect or whether it is meaningful.

Statistical analysis does not uncover important behaviours which might be infrequent and brief, but nonetheless potent, e.g. 11 seconds of jiggling may be exquisitely timed and perfectly performed to produce a rich response. Many events observed during the recording sessions were high in communicative significance for specific individuals, showing a clear difference between the three adult groups which could not be demonstrated through statistical analysis. The communicative significance of a behaviour can vary even between two people with a similar means of communication. Robert spent most of his time curled or crouched in postures which made interpersonal contact very difficult. Like Philip, he communicated principally through physical contact, but he did not react adversely to people being near or touching him: it was not a significant event if someone sat close or held his hand. However, if he tolerated having his arm jiggled this *was* significant. If he was not in the mood for social contact he would move away and could become annoyed if the activity persisted, although continual passive contact did not impinge in this way. In comparison to both these young people, Michael, a boisterous young person who enjoyed physical contact, frequently used touching to persuade adults to play and participate in specific games. It held no major significance when he permitted or initiated physical closeness and touching, and he was as ready to behave in this way with a stranger or his caregiver. In the same way, a direct look from Michael was less eventful than a direct look from Robert or Philip.

Sifting out meaningful behaviour and evaluating its communicative significance is no easy task. Is the young person who frequently initiates physical contact but does not look, smile or vocalise, doing 'better', 'as good as' or 'less well than' the young person who does participate in this way, but is never seen to initiate? Is interactive play which is focused on toys superior, inferior or equivalent to direct interaction between people? As Philip's profile will illustrate, sometimes it is what the adult is *not* doing which is effective, rather than being active. Philip enjoys sitting quietly beside his caregiver in passive physical contact, yet the potency of

this strategy of 'doing nothing' is difficult to quantify and is more effectively conveyed through descriptive information.

Descriptive observations help to describe behaviours that are meaningful to the young person and identify significant events. The significance of an event sometimes lay in the presence, as opposed to absence, of a behaviour, e.g. reaching out and cuddling a caregiver several times across the span of the four recordings, but never doing this with strangers. During the caregiver reviews, Robert's caregiver commented that it was what he was *not* doing that indicated he was taking notice of the other person - he was not turning away, he was not putting his hands out of reach and he was not displaying his usual activity, but holding his body very still. She felt there was 'something about his posture' that indicated he was attending to the adult. In this example there was no visible behaviour to record - its absence held the vital clue. Robert was usually inactive, so the stillness detected by his caregiver was not in marked contrast to a normally higher amount of activity. It was a qualitative difference, dependent on personal knowledge of Robert.

Though this qualitative difference was not obvious to the untutored eye, it was possible to detect it once it had been identified by the caregiver, but it remained very difficult to define. The anecdotal knowledge of caregivers offers a rich source of information which needs to be taken into account. As discussed in Study 1, this information is not acquired haphazardly by caregivers, but is built up systematically through their daily observations and experiences with the person with profound mental handicap. Caregivers have the greatest opportunity of seeing the person's many different moods and responses to people, places and events and can begin to build up a picture of how the person is likely to react in a given situation, thereby gaining an understanding of the meaning of physical behaviours, postures and vocalisations. Thus caregivers' accounts can offer a great deal of help in making sense of a person's style of communication and promoting effective interpersonal contact.

The profiles of involvement show how each young person distributed their interest and attention with each group of adults. 'Self-absorbed behaviour' is included instead of 'Solitary'. The latter includes physical

support and handling that had no communicative involvement, whereas the former offers a clear picture of absolutely no contact between young person and adult. Little information is lost, since self-absorbed behaviour accounted for most of the observations in the 'Solitary' category and information about rejection of contact, also included in this category, is included in the tables.

2. PROFILES OF INVOLVEMENT

2.1 Michael

Michael was twenty-two years old. He had emerged from a moody adolescent into a boisterous young adult who quickly withdrew his attention if an adult failed to capture his interest. On occasions an adult's failure to engage his interest provoked his anger. He readily responded to adults who did gain his attention, but would just as readily lose interest if the adult did not maintain a lively pace. Michael enjoyed a wide range of specific play and movement games, all of which had developed from his regular encounters with his caregiver.

The games between Michael and his caregiver were constantly developing and changing, though some remained firm favourites for a lengthy period. At the time of the video recordings Michael was beginning to enjoy quieter, more gently-paced movement games with his caregiver, these often lasting for periods of 20 - 30 minutes, e.g. exploring faces, playing with hands. Though responding best to his caregiver, Michael could adapt to other people who knew the kinds of games and play he enjoyed and, importantly, were able to incorporate the element of anticipation which he especially enjoyed. The difficulty for strangers, including those with experience, was his high expectation of specific events in playful encounters. Failure to live up to his expectations provoked a retreat into a sulk, or solitary play which excluded the adult.

It is impossible for strangers, even those with experience, to have inside knowledge of a young person within minutes of meeting for the first time.

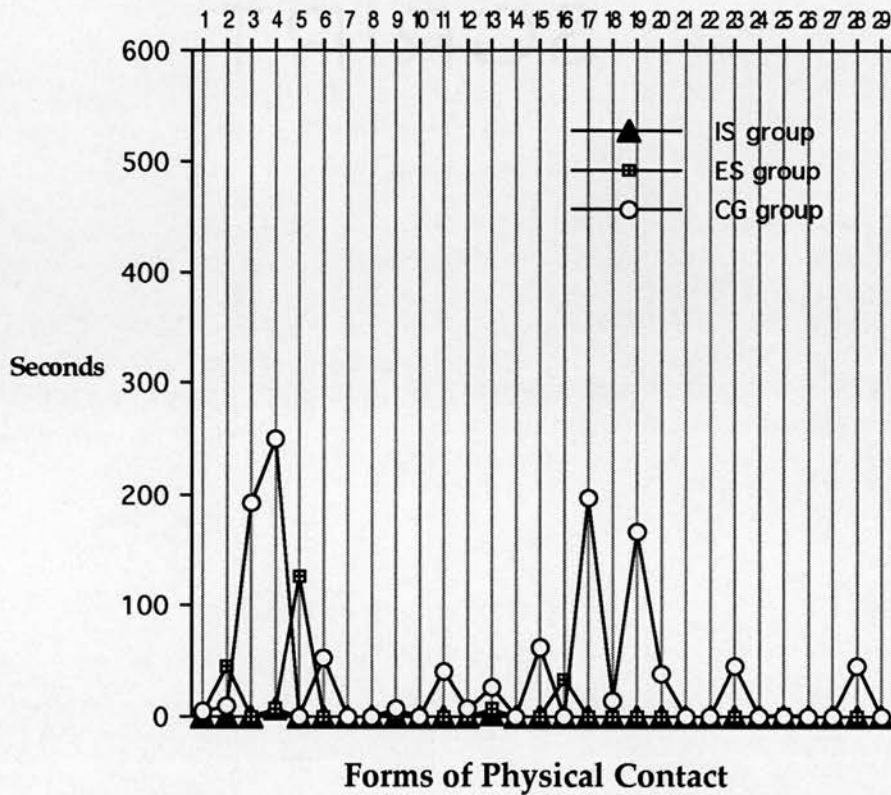
Michael's quick dismissal of failures gave little opportunity for trying and testing different ideas. The IS group reported being perplexed by his boisterous approach and then his withdrawal of interest. They felt that he did want to communicate but could gain no clues as to how to proceed. The ES group knew immediately that Michael was looking for specific responses. They knew he was waiting for them to do something, but could not work out what it was. They often guessed the activities accurately, but had difficulty in conducting the play in the ways he preferred, e.g. an ES adult might play the correct game with a squeaky toy but without the build up of the excitement he expected. Sometimes they would inadvertently meet his expectations, e.g. as they began to jiggle the teddy Michael started to dance. Unaware of what had triggered his response it was not surprising that they frequently chose the obvious, though wrong, trigger, e.g. believing the teddy was the interest rather than the jiggling action. In attempting to encourage more interest in the teddy, the adult would lose Michael's attention.

Michael's individual profile of involvement is shown in Table 8.1 and physical contact profile in Figure 8.1.

Table 8.1. Michael's profile of involvement

Mean Percentage of Time Spent in Level/Mode of Involvement	IS	ES	CG
Self Absorbed	79	51	0
Acknowledge	17	21	0
Passive Involvement	0	9	0
Active Involvement	1	5	4
Recip. Engagements	2	10	95
Initiation of Recip. Engage.	0	0	54
Total Number of Initiations	0	3	22
Total Number of MC/MTO	4	1	0
Total Number of Rejections	0	0	0

Figure 8.1 Michael



Michael was not especially interested in physical contact itself, but it was a prominent feature of the many games he enjoyed with his caregiver. The three adult groups showed very different patterns with Michael. The experienced strangers used a greater amount of active physical contact, while the inexperienced strangers confined their physical contact to hand-holding and resting against him, e.g. sitting beside him resting shoulder-to-shoulder. The caregiver showed an extensive range of physical contacts, with the high percentage of active hand contact reflecting the content of many of their games.

The profiles suggest that Michael's relationship with his caregiver plays a very influential role in his responsiveness and participation. Not only did he engage in reciprocal exchanges for most of the session, but he also initiated over half of the exchanges, suggesting that he had a great deal of control and influence over the communication. The partnership with his

caregiver is based on a variety of playful rituals, based on Michael's movements and sounds and the element of anticipation built up through regular and frequent encounters. It is not information that can be rapidly gained within minutes of first meeting and it is not surprising that strangers found him such a difficult communication partner.

However, the relationship is not exclusive: Michael does respond to others and, providing they offer something to maintain his interest, shows a willingness to become involved with them. Some of his responses are described in the following examples.

Michael was in a session with an inexperienced stranger. Near the beginning of the session Michael sat down in a chair with the adult standing beside him, holding a teddy she had just picked up from the floor. Michael watched the adult with a smile and she began to rock the teddy in a sideways motion. Michael lost interest after six actions, stood up and picked up a second teddy which he began jiggling. He offered the teddy to the adult several times, which she accepted on each occasion, commented on the teddy and handed it back to Michael. After several such exchanges Michael began to rock on his own, watched by the adult sitting in a nearby chair. Michael stopped after thirty seconds or so and took the adult's hand, leading her several steps away from the chair, maintaining eye contact and smiling. He began to play with her hands and in response to his to-and-fro motion the adult said, "oh, are you dancing?". Michael then pushed the adult's right hand down with both his hands, took hold of both her hands and appeared to prompt a sideways swaying motion which the adult continued for three actions. At the end of the third action Michael held his hands still and stopped the action. The adult tried to continue the swaying motion, saying, "do you want to dance?", but Michael moved instead to sit in the chair, though he continued to hold the adult's hand and maintained the eye contact and smiling. Several seconds after sitting down he dropped eye contact and looked at the floor.

Reviewing the recording, Michael's caregiver thought that the adult's actions were performed at too slow a pace to capture his interest. However, the adult did not fail to make interpersonal contact with him - he did show an appreciative awareness of her presence through his smiles, continual looks, toy offers and his several attempts to 'get things going'. The adult watched Michael carefully throughout and was guided by his actions, e.g. his 'dancing' prompt, and her gentle manner created a pleasant atmosphere. In fact she was *too* gentle, but although the slow pace subdued his usual exuberance her sensitivity to his actions appeared sufficient to maintain his interest in her.

In a second example Michael entered the recording room in a happy, boisterous mood and went directly to the (IS) adult, smiling and looking at him. The adult sat down on the play mat, stretched out his hand and said, "are you going to play", his face unsmiling and body remaining still. Michael immediately became very still and his face went blank, although he continued to watch the adult. Both watched each other for thirty seconds or so when Michael went across to the chair in the corner of the room. He began rocking, with a less expansive action than usual, continuing to watch the adult who in turn was watching Michael but attempting no intervention. Michael then began to look around the room, his face remaining blank, all the while rocking. The adult moved to a chair several feet away from him and continued to watch. Michael then brought his hand up to his face and focused intently on the palm of his hand, still rocking. The adult threw a ball towards him and several soft toys which were ignored, Michael continuing to rock. The adult then moved his chair closer and offered a squeaky toy which Michael accepted and then handed back. At this point he stopped rocking. The adult repeated this toy routine for several minutes until the end of the session. Although Michael complied he did not look at the adult and his face remained blank.

His caregiver described his behaviour during the latter exchange of toys as a 'typical sulk' and the earlier focusing on hands as 'a sure sign that he's switched off.' Her opinion was that Michael was annoyed by the adult's inertia. He did not appear distressed or anxious, but did seem discomfited by the adult's failure to engage. The adult did not offer Michael any communication behaviour which harmonised with his own. The adult in the first session may have performed her actions too gently, but her smiles, pleasant facial expression and constant and *active* monitoring of what Michael was doing at least conveyed a sympathetic interest.

2.2 Philip

Philip was nineteen years old. He was very withdrawn, preferring to be alone most of the time. However, he did approach people he knew well from time-to-time and take their hand or give a brief hug or sit on their knee. These moments lasted briefly and were usually ended as abruptly as they began. He played constantly with a piece of string and was very adept at finding new supplies. When interested in a person or activities he could take his attention off the string but needed to keep it in his hand or within sight. Caregivers did not make an issue of this and it did not present a difficult communication barrier. The greatest barrier was his fearfulness of close proximity with others. He protected himself by keeping well apart, giving no acknowledgement of the other's presence

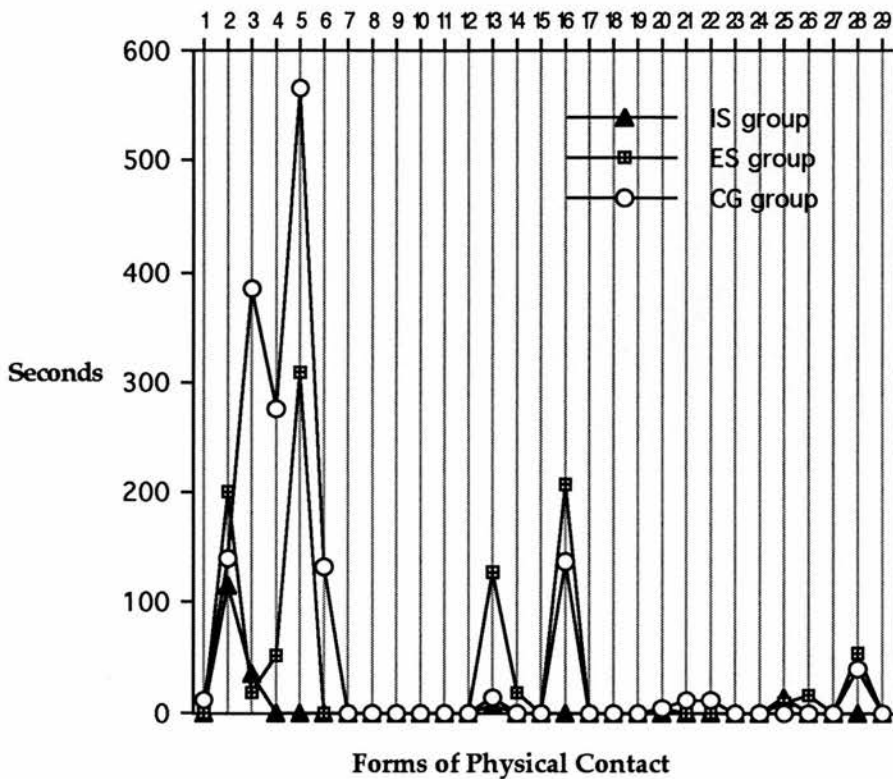
and intensifying his focus on the string. If an adult moved closer he simply moved further away to maintain his preferred distance. Thus he was able to control how much he became involved with the adult during recording sessions. He did not become distressed on any occasion and entered the room willingly, with no signs of anxiety or wanting to leave during any of the sessions, his nonverbal message to 'keep your distance' being obvious to both groups of strangers.

He frequently held his breath, opening his mouth wide, stretching his head back and freezing his posture, then letting go with a loud sigh. To the uninitiated this looked like yawning and most strangers reacted as if it were. Thus it was interpreted as 'normal' behaviour and was not off-putting for strangers to witness. However, it did interrupt the flow of events. For example, if he did this while adults were trying to engage his attention it usually stopped them in their tracks and they would change what they were doing, assuming he was yawning. They usually commented that he must be tired or bored and reorganised their approach on this assumption. On the other hand, his caregiver was unaffected by his 'yawn' and she was not stopped in her tracks. Sometimes she gently massaged his face and neck, helping to bring him back to normal posture and breathing. Philip's individual profile of involvement is shown in Table 8.2 and his physical contact profile in Figure 8.2.

Table 8.2 Philip's profile of involvement

Mean Percentage of Time Spent in Level/Mode of Involvement	IS	ES	CG
Self Absorbed	73	16	4
Acknowledge	9	21	0
Passive Involvement	11	37	71
Active Involvement	0	31	12
Recip. Engagements	0	2	7
Initiation of Recip . Engage.	0	0	0
Total Number of Initiations	2	12	6
Total Number of MC/MTO	0	6	0
Total Number of Rejections	5	8	0

Figure 8.2 Philip



When he was younger Philip would become very upset and agitated if anyone approached him within a few feet, and had frequent bouts of screaming when he was unable to move away or if there was physical contact. Using a slow, unhurried approach, his caregivers have gradually increasing the closeness and touching that Philip can tolerate and now, despite his timidity and preference for being alone, Philip communicates mostly through physical contact. Both the ES and CG groups spent similar percentages of time in active hand contact, the form of contact which seems most effective in eliciting and maintaining his involvement. His caregiver also spent a substantial amount of time sitting beside him, maintaining body contact but not pursuing active contact. Philip enjoys being physically close to someone he knows and trusts and will initiate this on occasions. Given his immediate appearance of timidity and isolation, it is interesting that the ES group quickly recognised Philip's preference for communicating through physical contact. They reported that his cues made immediate sense in the light of their previous

experience with other similarly withdrawn young people. This suggests that Philip's adverse reaction to and preference for physical contact may not be an idiosyncratic paradox.

It is clear from the high percentage of time Philip spent in self-absorbed behaviour with the IS group that they did not fare well in their attempts to encourage communication. By comparison the experienced strangers and his caregiver has greater success. Yet when the distribution across the levels of involvement is compared between his caregiver and the experienced strangers, the ES group appears to have had the greater success. The caregiver did achieve a higher percentage of reciprocal engagements, but the ES group elicited more than double the percentage of active involvement as the caregiver and Philip initiated some form of contact with them more often. By contrast, involvement with the caregiver was principally passive. Philip provides an example of the difficulties encountered in assigning judgements to interpersonal events with people with profound mental handicap. Philip and Michael have the same caregiver. When with Michael she is seen to be very active and vocal and to keep the pace going. This suggests that her preparedness to accept such a high percentage of passive contact with Philip, with no prompts to quicken the pace or encourage more activity, is a deliberate approach.

Most of Philip's interpersonal contact is through physical contact and proximity. When Philip sits down close by someone it is a significant event; when Michael does this it is mundane. Philip appears comfortable and relaxed with his caregiver and gives the impression of enjoying simply being beside her. They could be described as enjoying a companionable silence. There is nothing else on the agenda. Philip highlights how personal relationships cannot be measured solely by amounts or frequencies of behaviours.

Philip was observed only to initiate with the ES group. Does this mean that he wanted more contact with this group than with his caregiver? Were their actions prompting more interest? In fact, when the recordings are studied it can be seen that Philip is prompting the experienced strangers to carry on patting and stroking his hands. In these instances the adults have stopped and are sitting quietly or trying to interest him in

something new. Philip holds out his hand towards the adult indicating clearly that he wants the hand patting and stroking to continue. When these cues are missed he lapses into self-absorbed behaviour. His initiations are prompts which accounts for their absence with his caregiver. She is tuned in to his communication needs and prompts are unnecessary. His lack of such prompting with the IS group suggests that some degree of involvement with the adult is necessary before he will indicate his wishes. It might also be possible that he rarely prompted the IS group because he knew his actions would not be understood.

Given his solitary nature it is not surprising that Philip rejected the interventions of adults on occasions, although a total of thirteen rejections over a collective recording time of seventy two minutes is very low. However, this category refers only to overt acts of rejection. In Philip's case the caregiver's review suggested that there was also hidden rejection, characterised by inactivity as opposed to an active rebuff, as illustrated in the following extract from a review:-

Philip is with an experienced stranger. He takes the adult's offered hand as she sits down and begins speaking quietly to him. She pats and strokes his hand while he sits facing her with a relaxed posture. She introduces a ball, trying to encourage a game, touching his hands, arms and knees lightly with the ball. Philip sits during this with his right hand outstretched. His caregiver comments that at this point he would prefer the adult to take his outstretched hand and leave the toy alone. The adult mistakes his action, assuming he is reaching out for the ball and places the ball in his hand, at the same time touching his left hand with her free hand. Philip opens his left hand and lifts it towards the adult, while letting the ball drop out of his right hand. While the adult continues tries to attract his interest Philip withdraws all participation, but he reacts immediately when the adult stretches her hands towards him. However, he lets his hand drop when she turns to pick up the ball and again he withdraws from participating. Around thirty seconds later, during which the adult has tried to interest him in play with the ball but has not forced his participation, he allows the adult to take his hand. Again she views this as an opportunity to persuade him to play with the ball. Philip stretches his hand out towards the adult wanting hand contact which she interprets as a request for the ball and she places it in his hand. Philip turns his head far round from the adult and throws the ball away. The adult comments as if he meant to throw it, "that's right, that's good." Philip withdraws into self-absorbed behaviour.

Throughout this episode the adult interpreted Philip's open and outstretched hands as signs that he wanted to play with the ball. When Philip threw the ball away she thought it was a playful act. Her pace and

manner was gentle and so he was not forced into a complete retreat and he clearly felt relaxed enough to remain beside her. It is likely that in this good mood he would have participated in active exchanges through hand movements and seemed to be trying to prompt this. His rejection of the adult's ideas was hidden in two ways - his hand movements were open to alternative interpretations and he did not use overt actions to reject. Even the one overt action he did use was misinterpreted as a sign of participation. His caregiver spotted his wishes immediately and forecast correctly that he would switch-off his attention.

2.3 Mary

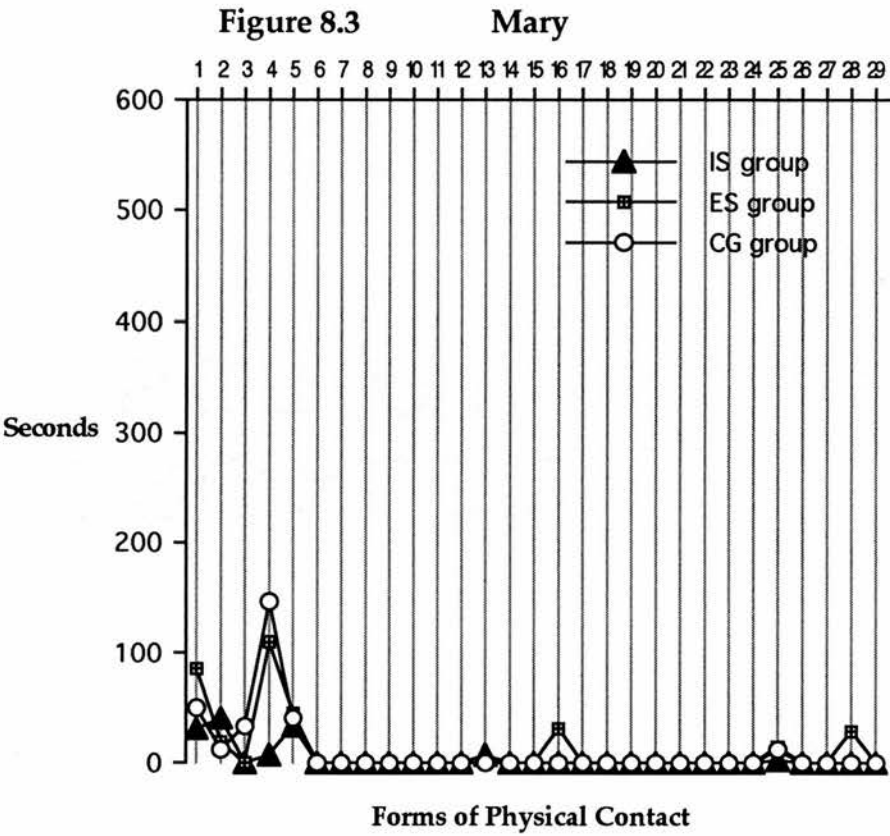
Mary was twenty-one years old. She had frequent epileptic seizures and, though not physically handicapped, often had a very unsteady gait. At such times she also had difficulty in maintaining her balance while standing or sitting. She had a very frail appearance, but was surprisingly robust and had weathered many crises in her health. She gave frequent eye contact, usually in the form of many glances rather than longer looks. She also communicated through smiles, hand contact and by bringing her face very close to the other person and looking directly at him or her. She initiated mainly through eye contact and smiling. She would reach out and grab objects and made a 'boo' sound when happy. She showed her dislike by a 'huffy' face, moving away, pushing the other person away, throwing objects away or biting her hand.

Mary would move across the room to someone to make social contact but the actual encounter needed to be in close proximity. She responded well to close facial contact and face games, e.g. rubbing noses, pulling faces. Other people needed to keep close facial contact and make faces. She liked being spoken to and needed physical contact, though her caregiver felt that close proximity rather than actual touching was the most important element. She observed that inexperienced strangers were often not close enough and held their faces too far away.

Mary's individual profile is shown in Table 8.3 and her physical contact profile in Figure 8.3.

Table 8.3 Mary's individual profile

Mean Percentage of Time Spent in Level/Mode of Involvement	IS	ES	CG
Self Absorbed	78	47	33
Acknowledge	9	17	17
Passive Involvement	9	16	16
Active Involvement	0	8	5
Recip. Engagements	0	4	19
Initiation of Recip. Engage.	0	0	0
Total Number of Initiations	1	6	0
Total Number of MC/MTO	3	0	0
Total Number of Rejections	2	4	1



Mary did communicate through physical contact, but this was not her principal means of communication. She responded best to nudges, tickles

and briefs pats on her face, limbs and body and she generally elicited this form of physical contact from the ES group as well as her caregiver. The IS group did pat and tickle her hand but not her body and though this could be effective, her hands were frequently tucked underneath her head or body as she lay crouched on the floor in her usual position. Mary's physical contact profile shows the least variety of the six PMH subjects, her needs being honed down to those which gained and held her attention.

The missed cues, though small in number, had an important effect as illustrated in the following examples:-

Mary ended an episode of solitary activity by glancing at the adult who appeared not to notice. On receiving no response she immediately withdrew into further solitary activity. The glance lasted less than one second, allowing the adult only this brief moment for an immediate response.

On the second occasion Mary had been more responsive than usual, with longer looks to the adult's attempts to gain her attention and showing an interest in some toys. She seemed to tire of one of the toys and pushed it aside, but then immediately looked directly at the adult for just over three seconds. The adult was half-turned away from her searching for another toy and missed her look and Mary withdrew into solitary activity.

The third missed cue was also a direct look towards a different adult who again was choosing a toy and Mary again withdrew into solitary activity.

On all three occasions the adults had to work hard to regain her attention. It was not unusual to have difficulty in attracting Mary's interest, but her immediate withdrawal when her cues were missed and the subsequent difficulty in gaining her attention suggests that the adults had 'missed their moment' and had to work hard to make up for this.

Mary's physical ability fluctuated widely during the recording period. She had a difficult spell midway, in which her balance was extremely poor and she was unable to walk or sit without falling over. She remained physically active and could be very determined about achieving what she wanted despite repeated failure, e.g. striving repeatedly to sit up despite overbalancing as soon as she was upright. The ES group and her CG were less worried by these events than the IS adults, supporting Mary more confidently and able to salvage a greater amount of communicative contact.

In one session Mary's caregiver turned her struggles into a game:-

Mary was lying on a mat with her caregiver sitting alongside. Mary moved to sit up, assisted by her caregiver who then supported her with an arm round her back, maintaining a face-to-face orientation. The caregiver then began to make Mary's 'boo' noise, zooming into her face and playing face games. Mary responded with sounds and long looks until she started to topple over to one side. Her caregiver supported her down onto the mat where Mary remained for around twenty seconds before struggling to sit up again.

A similar cycle was repeated throughout the session, with an episode of communicative contact during each spell of sitting. When Mary overbalanced or struggled up her caregiver reflected the effort with her voice, commented on what Mary was doing. In this way, her actions were used to make contact rather than being allowed to interrupt the flow. ES adults were also observed to use similar tactics.

2.4 Robert

Robert was fourteen years old and lived in an isolated world cut off from other people. Though preferring his own company he did not appear anxious or timid of people. He showed no anxiety when people were close to him or touched him and made no attempt to move away. He appeared to be wrapped up in his own actions, fending off intruders as nuisances rather than threats. He adopted postures which made communicating with him very difficult, adding new twists and turns to his body if his barriers were breached, usually keeping his face well hidden.

Direct eye contact was rare. Though he sometimes gave a long intense stare, more usually he gave a brief glance. When responsive he would put his hands out to be touched and take hold of other people's hands to play with them. His forms of initiating contact were the same as those he used to respond. He showed his dislike and rejection by turning his back, walking away, or pushing the person away. He became annoyed if made to participate when he did not want to do. When switched-off he kept his hands at his face, mouth or neck.

He would tolerate other people for short periods only. People had to be very close to him to gain his attention: he would not walk across the room to initiate or respond to contact. His caregiver observed that the IS group did not have enough physical contact and were not close enough. Robert preferred firm and steady handling rather than gentle touch. His caregiver spoke firmly to him to attract his initial attention then would repeat her verbal request and touch him to encourage further involvement. He would not turn round to look at objects and toys - they had to be held close and in his line of vision.

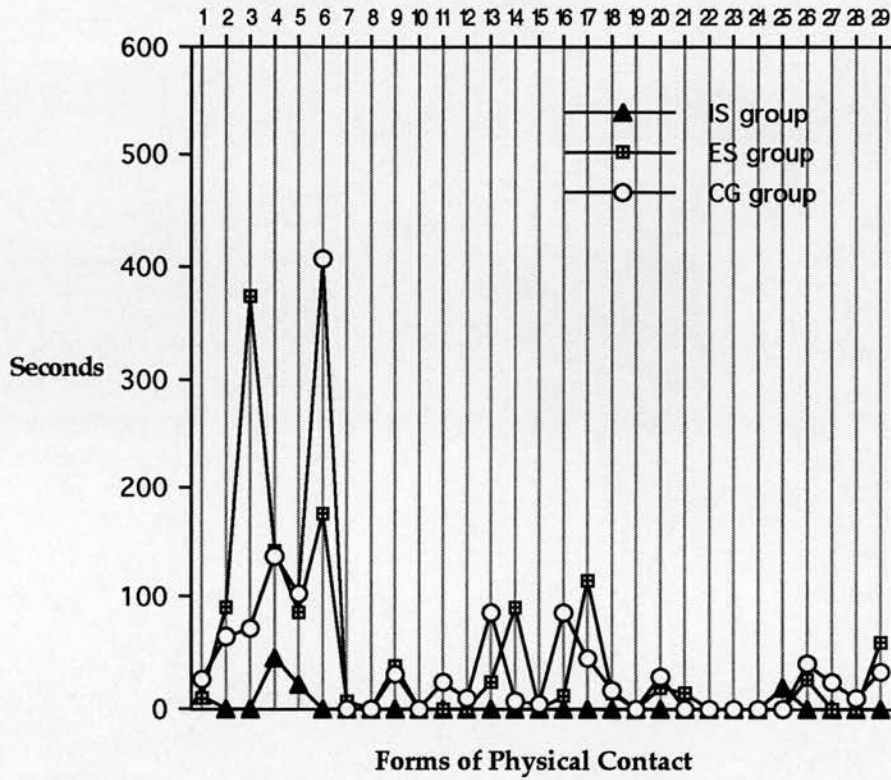
He liked hand play, exploring faces and, on occasions, gave long penetrating looks. On occasions he enjoyed being tickled, which his caregiver exploited and this often lead on to other forms of contact. When responsive to tickling he would laugh and giggle, then wriggle away but remain nearby, ready to respond to the next bout. When he was in no mood for any contact the same tickling produced no response. Robert's profile of involvement and physical contact profile are shown in Table 8.4 and Figure 8.4.

Table 8.4 Robert's profile of involvement

Mean Percentage of Time Spent in Level/Mode of Involvement	IS	ES	CG
Self Absorbed	78	12	11
Acknowledge	11	1	7
Passive Involvement	8	49	50
Active Involvement	0	30	21
Recip. Engagements	0	1	5
Initiation of Recip. Engage	0	1	3
Total Number of Initiations	0	16	25
Total Number of MC/MTO	0	0	0
Total Number of Rejections	2	0	1

Figure 8.4

Robert



Robert preferred communicating through physical contact. Unlike Philip, he did not shy away from it, but he made it very difficult for adults to find a way of making contact and prompting communication. Adults usually had to work very hard with tickles, nudges and pats, and stroking his head and face, before he made a response. Despite the length of time an adult might have to spend employing these tactics, this physical approach seemed to work best with Robert. Body contact was the largest single form of contact observed in both groups. In the ES group this was passive, with Robert and adult resting against each other, while his caregiver used more active body contact, e.g. rocking him to and fro. Robert gave very clear indications that he enjoyed body contact, relaxing and moulding into the adult's body shape. The ES group were able to recognise and respond to this, but his caregiver knew from her personal knowledge that he also enjoyed more active contact. Lacking this knowledge, the ES group could not be sure that activity would not break the rapport created by the passive body contact.

Robert spent fifty percent of the session in passive involvement with the ES group and his caregiver, but he was also actively involved with the these two groups for around 1¹/₄ -1¹/₂ minutes of the six-minute session, voluntarily joining in active communicative exchanges. On average he initiated one brief reciprocal engagement with the experienced strangers during the session and had several brief engagements with his caregiver, some of which he initiated.

However, the feature which is perhaps most out of step with his withdrawn and passive profile is in the number of events overall (rather than reciprocal engagements alone) which he initiated with the experienced group and his caregiver. Putting this information together, a more active picture emerges. Over four sessions with his caregiver he initiated twenty five times, spent fifty percent of the session permitting closeness and touching, one fifth of the session in active involvement and participated in and initiated brief episodes of reciprocal engagements. He spent fifty per cent of his time with the ES group accepting closeness and touching from a complete stranger, was actively involved for three-fifths of the time, initiated a brief reciprocal engagement and initiated events 16 times over four sessions.

However, Robert is extremely hard work for his communication partners and his participation is not gained easily. The picture with the IS group is quite different. He spent an average of only forty seconds in his sessions with this group showing an awareness of their presence. A typical picture of his sessions with inexperienced strangers is described below:-

In this session most of Robert's behaviours were categorised as 'self-absorbed'. He glanced three times at the adult and there were four physical contact events, all brief, which took the form of pats or the adult resting a hand on Robert's hand or arm. There were two events involving toys. Robert glanced at the teddy the adult was waving to attract his attention and in the second he examined the teddy for a longer period before turning away. These three glances to the adult and the two inspections of the teddy suggested that Robert did have some interest or curiosity in what was happening and was not impervious to the adult. The observations do not give a clue as to the reasons for his interest: was he tracking the adult so that he could fend off intrusions into his self-absorbed behaviour, or was he displaying an interest in what the adult might do next? His caregiver felt that he was keeping an eye on the adult so that he could fend off intrusions. These were minuscule cues, yet they reveal

events which were triggered by the presence of another. The inexperienced strangers actions influenced Robert's actions, even if fleetingly.

Even when he was actively involved, Robert's participation remained fragmented and required a steady input from his communication partner, as demonstrated in the following example:

Robert was lying stretched out on the mat, with his back turned to the adult, his face inches from the floor and resting on his hands. The adult sat on the floor patting and stroking his feet. Robert brought a hand down and touched his feet, but did not look towards the adult. He 'doodled' with a foot and then the adult's hand. He turned on to his side and the adult took the opportunity to pull him up to sitting in a sideways orientation to her. He started to lie down again but the adult patted his hand with quick actions and he righted himself to sitting again. He put his head down, one hand in his mouth and twisting and intertwining his other hand round the adult's hand. She 'doodled' in this way for a minute or so occasionally speaking quietly, but mostly remaining silent and focusing on his hands. The adult moved round slightly so that their orientation was more direct, but not face-to-face. She patted Robert's hand and stopped and he patted her hand in return and stopped. The adult held her hand still, focusing her attention on Robert but remaining inactive. Robert sucked his hand and focused on a spot in the distance, then he looked at the adult's hand and patted it with his free hand several times, she patted back and he patted again. Leaving his hand resting on the adult's hand, he turned his head, raised it slightly and looked at her with a direct gaze for several seconds - the first time he had looked at her. He dropped his gaze, glanced again and then hunched over, but remained seated beside the adult. She continued to pat his hands and feet and talk quietly to him and from time to time he 'doodled' with her hands, but he did not look at her again.

Both Robert and Philip communicated principally through physical contact, but their different patterns of contact serve to emphasis the importance of adjusting its use to the needs and preferences of the individual.

2.5 Sean

Sean was twenty-six years old, tall, good looking and with a normal appearance which belied the severity of his handicap. It was easy to be unaware of his difficulties, until his behaviour revealed otherwise. He had severe epileptic seizures which affected his mood beforehand and he needed a long recovery period. He responded well to others through his

smiles and physical actions, e.g. taking the person's hand, looking into the person's eyes, giving a hug. He was very gentle and gave a very rewarding welcome to people he liked and knew well. His facial expressions showed his feelings and in general his face and manner showed his mood instantly.

Sean spent a lot of time spectating - he liked to watch the events around him, but would only join in if he was in the mood.

Sean showed recognition of people and activities, e.g. he could guess which game his caregiver was going to play from her preparatory actions. She felt a sense of sharing was imparted by his style of participation, e.g. when out for walks, she felt he walked *with* her rather than being taken for a walk. His caregiver often started their encounters by approaching him with arms open wide and hugging him, skipping with him with arms round each other's waist and spinning him round.

Sean liked playing with and inspecting hands, rings and watches and his attention could be attracted by shaking a bunch of keys. People had to 'keep at him' to maintain his attention and needed to be close - his caregiver noted that the strangers in the recordings were often too far away. He would not do things for someone, e.g. sitting down to play with a toy, the person needed to be with him and do things together.

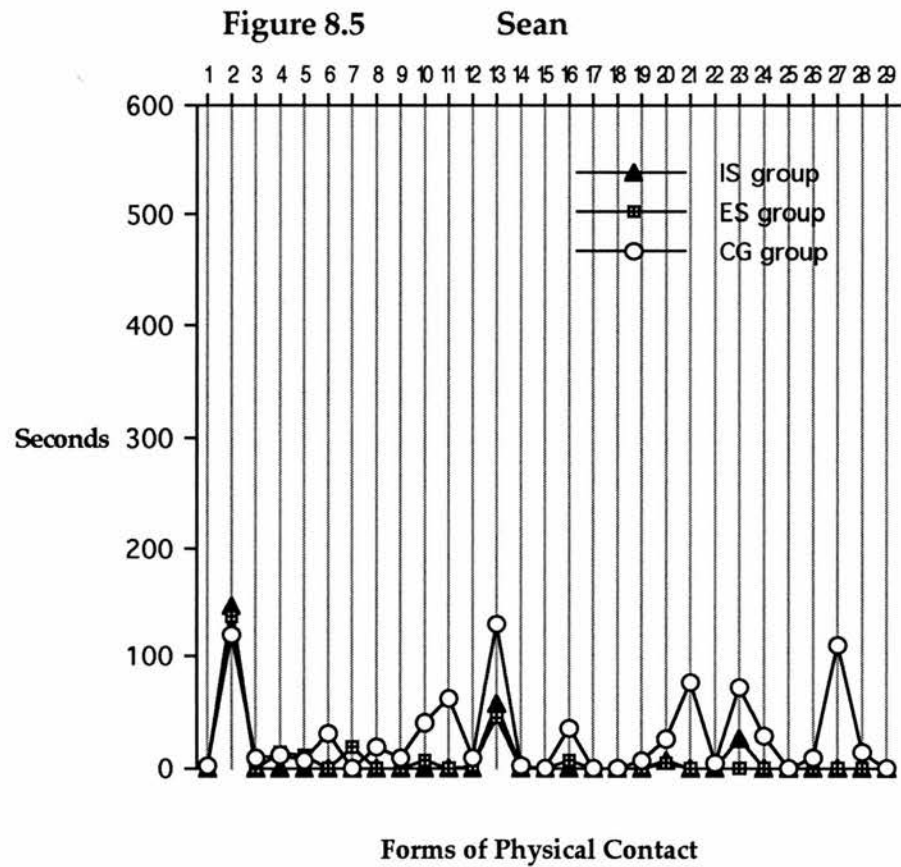
He screamed to get rid of tension when upset and angry and sometimes clapped his hands. High-pitched vocalising meant he was happy, as did dancing and being up on his toes. If he was in a bad mood he would still give a hug but it was rougher, though his hugs became more gentle as his mood improved. If Sean was in a very bad mood it showed in his eyes and face and it was best to leave him until he was feeling better.

Sean's individual profile is shown in Table 8.5 and his physical contact profile in Figure 8.5.

Table 8.5 Sean's profile of involvement

Mean Percentage of Time Spent in Level/Mode of Involvement	IS	ES	CG
Self Absorbed	60	57	11
Acknowledge	18	12	17
Passive Involvement	0	3	7
Active Involvement	16	23	32
Recip. Engagements	4	1	27
Initiation of Recip. Engage.	0	0	1
Total Number of Initiations	29	22	34
Total Number of MC/MTO	4	1	0
Total Number of Rejections	*3	0	0

*Walked out of room on 3 occasions with 3 different inexperienced strangers and came back voluntarily shortly afterwards. This appeared to be more a part of his aimless wandering rather than outright rejection of the adult's presence.



Sean offered the most difficult challenge to the IS group. He was of similar age to the students in this group and his normal build and lack of 'handicapped' features had an inhibiting effect on them. Unless Sean approached them, they generally remained stationary at a distance from him. Sean liked to pace about and in the recording room usually paced around watching the adult, looking at the cameras, fidgeting with the door handle and the curtains. With three of the IS adults his pacing led him out of the recording room into the day room, from where he either wandered back into the recording room or returned readily when asked. The adults seemed to relax more when Sean behaved at odds with his appearance, giving some confirmation of his handicap. Sean obliged in this way in all his sessions, the following session providing a typical example:

The (IS) adult was sitting on a mat on the floor, having tried unsuccessfully to persuade Sean to play after he had fidgeted with several toys. He began his usual pacing, moving round the edges of the room and stopping at different times to fidget with the fixtures and furniture. He was silent, but had a pleasant grin and the adult appeared relaxed. When Sean reached up to the camera, only just within his reach, the adult moved across and led him into the centre of the room, trying to divert his attention to the wall mirror. Sean ignored the mirror and wandered off, still grinning, and resumed his round of fidgeting. He frequently looked at the camera and stopped underneath it each time he passed by. The adult, who had remained standing, watched him closely but did not make any approach. Sean then moved across the room and looked up, his back now to the adult. His grin spread across his face as he reached up and began to pull a microphone and several yards of cable down from the ceiling. This happened quickly and unexpectedly and the adult did not react immediately, but once she realised what was happening she moved across and led him away to the other side of the room. Sean began to fidget with her hands and she remained with him, allowing him to play with her hands, talking more to him and walking round with him when he resumed pacing.

Although it was probable that the adult remained near him to prevent any repetitions with the microphone, she also appeared more ready to respond to the hand play he enjoyed and to move round with him, thereby gaining

his interest more effectively. The adult had a difficult experience with Sean and coped well with his behaviour and, in fact, the experience seemed to prompt a better rapport. It is impossible to say whether the adult was able to cope because of some aspect of her medical training or her personal qualities, though the earlier example of an IS adult's difficulty with Philip suggests the latter.

All the IS group reported favourable feelings towards Sean, despite the difficult time he gave them. Their hesitancy on first meeting him was dispelled as they watched his actions (and antics), although they remained generally perplexed about how to proceed. The ES group dealt more confidently with Sean's fidgeting, nipping this in the bud by direct intervention or attracting his attention elsewhere. They rarely remained still, but moved around the room with him, monitoring his actions. They readily made hand contact and all the adults used his obvious interest in this form of contact by patting and playing with his hands when he began to fidget - an effective strategy which none of the IS group discovered.

Sean initiated much of his interactive involvement through physical contact, showing the greatest amount and variety with his caregiver. He enjoyed and initiated lots of close body contact, but not with strangers. However, he did like hand contact and playing hand games with anyone, although his caregiver was the only adult to extend the hand contact he initiated into hand games in which they were both involved. These were exchanges based on many previous encounters and well-known to both. The experienced strangers used a lot of active hand contact and it is likely that, given time, this would have led to more extensive forms of contact and communication. They were able to recognise that this was a 'way in' to communicating with him. Inexperienced strangers found it very difficult to establish communication with Sean, who 'held back' from strangers, standing at a distance and watching them, but not becoming involved.

2.6 Terry

Terry was eighteen years old. Unlike the other five PMH subjects he had additional physical impairments. He had a slow, awkward gait and required a wheelchair for outdoor excursions or lengthy walks, though he was stronger and more mobile than Mary. He gave clear signs of his likes and dislikes, e.g. by smiling. During play and communication Terry's caregiver constantly repeated everything he responded to and copied what he did to see where it would lead, e.g. he patted his chest a lot and so she copied this, extending it to play with a ball where she patted his chest and body with it. This in turn developed into a repertoire of games, e.g. he laughed when the ball fell through his legs as he tried to catch it and so this became a deliberate game.

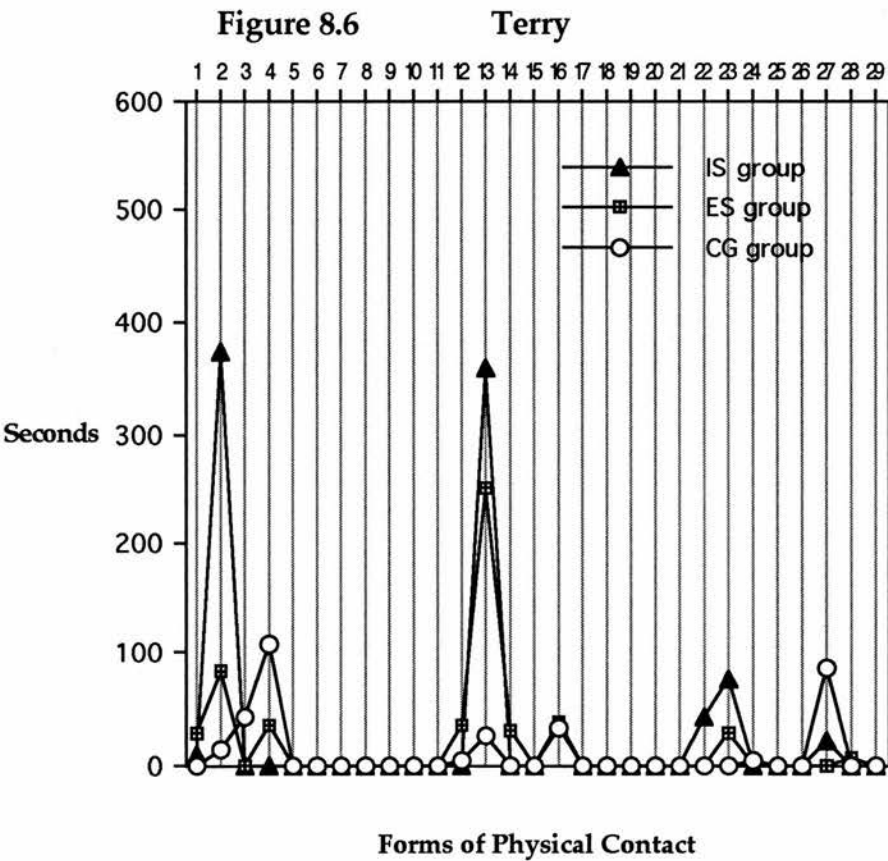
His caregiver found that she had to stay close to him and keep adjusting to his level, e.g. crouching down with him. People had to keep the activity constant with no pauses and needed to do things fast to interest him and maintain his attention. On the other hand, she expected and was prepared for him to be slow in his responses - it took a while for him to make his response but she knew it would come. She incorporated frequent body contact into their games, e.g. walking a toy up his arm, bouncing the ball on his head. If she was doing something and Terry changed it, she changed to his choice. If the caregiver was playing with a toy and Terry grabbed or held on to it, it meant he liked the toy and she turned it into a game. Terry recognised games that he and his caregiver played often and smiled and laughed when he saw them start up.

Terry put his thumb in his ear and kept his head down and body bent over when he did not like the sound of a voice or toy, or was in a bad mood or 'switched off'. If Terry was upset his caregiver just sat with him and talked to him, but did not expect him to make a response. She did not expect him to respond every time she approached him - it depended on his mood and how he was feeling.

Terry’s individual profile is shown in Table 8.6 and his physical contact profile in Figure 8.6.

Table 8.6. Terry’s profile of involvement

Mean Percentage of Time Spent in Level/Mode of Involvement	IS	ES	CG
Self Absorbed	23	25	13
Acknowledge	22	27	17
Passive Involvement	26	5	0
Active Involvement	11	14	13
Recip. Engagements	5	29	54
Initiation of Recip. Engage.	0	0	4
Total Number of Initiations	21	21	2
Total Number of MC/MTO	8	0	0
Total Number of Rejections	2	0	0



Much of the hand-holding used by the IS group was observed with Terry. He gave the appearance of being unsteady on his feet and in need of physical support, although this was not the case. Terry also initiated a large amount of hand-holding with the IS group and, to a lesser extent, with the ES group. It did not appear to be a strong feature of his communication and was not used extensively by or with his caregiver. Terry seemed to like holding on to the adult during quiet periods in the sessions. If an adult was trying to draw his attention to toys he would take hold of the adult's hand while watching. In contrast, most of the hand holding he initiated with his caregiver had a purpose, e.g. he would take her hands and begin swaying, prompting a favourite rocking game. His caregiver used little hand-holding, but was observed to use frequent, brief bursts of active contact, e.g. walking a toy up his arm. This active contact was strategic, generating an excitement that attracted his attention and held his interest.

Generally, physical contact formed an element of Terry's style of communication, but it was not a prominent feature. However, the IS group exhibited more physical contact with him than with any other subject. It may be that Terry's appearance gave them 'permission' to touch, or at least to hold his hand, and this was further encouraged by Terry himself. When Sean initiated hand-holding with the IS group they were unsure of how to react. His normal build, height and appearance hid his 'handicap'. Yet hand contact was a prominent feature of Sean's style of communication. The experience of the ES group seemed to help them to overcome the impressions of physical appearance and respond more appropriately to the individual young person.

All four ES adults reported feeling that Terry was trying to show them what he wanted to do, but they did not know him well enough to decipher the meaning of his actions. Unlike Michael, he was not angered by their lack of understanding and he also persisted for longer. Frequently, he was trying to start games with the ball, but his actions, often clumsy and poorly co-ordinated, were not clear to those who did not know him and some were open to a number of interpretations. The ES adults could be observed working their way through the possibilities and through this

detective work they were sometimes able to guess his intentions correctly. The following example describes such an occasion:

The ES adult had engaged Terry's interest from the beginning of the session, playing with the ball, walking round the room with him and playing inventively with the other toys. Terry and the adult were standing together during a pause after a game with the ball. Terry stood with one hand resting on the adult's wrist, holding the ball in his other hand. He raised the ball and clumsily patted his forehead and upper body several times. The adult asked if he wanted to repeat the ball game and started to play. Terry smiled and watched her actions, but did not join in the game. The adult paused and watched Terry, asking him what he wanted to do. Terry patted the ball on his forehead and pulled on the adult's wrist with his other hand. She took this to be a prompt to move forward and began walking with him, but stopped immediately when he stopped. Terry turned and faced the adult, still holding on to her wrist, again patting the ball on his forehead. From her comments, it was now very clear to the adult that he was trying to prompt a specific response. Terry pulled on the adult's hand and this time she began patting his head. Terry's hand was still holding her wrist and, as she reported later, he guided her into a stroking rather than patting action. At this point it became clear that he was trying to get the adult to stroke his head. Once she began doing this he stopped prompting.

The young people's cues were often unconventional and they did not always choose the easiest prompts. The adult in the above example worked through the possible interpretations systematically, waiting to see if he responded positively before moving on. She focused on what he was trying to tell her, introducing no new activities nor diverting his attention to a new game. Thus, the adult also played a part in reaching a successful conclusion. It is interesting that, several minutes later, when Terry prompted the adult to pat his chest with the ball, she understood his intentions more quickly, and that she did not confuse his very similar prompt with the earlier one. Within the space of three or four minutes she had gained sufficient personal knowledge of Terry to be able to make such distinctions.

The profiles show very different individual pictures of the ways in which the young people communicated and the extent to which they became involved with familiar and unfamiliar people. Terry persisted when his cues were misunderstood, whereas Michael retreated into solitary play and ignored the adult when expected responses were not forthcoming. Information about individuals can hold the key to gaining the young

person's involvement. The therapist meeting Michael for the first time would find it helpful to have prior information about the games he enjoys whereas information about Philip's preferred forms of physical contact would be more helpful in his first session. The caregivers were shown to be a vital source of this information, possessing a rich personal knowledge of the young people which is an invaluable asset in gaining an understanding of the young person's actions and responses.

CHAPTER 9

ACTION CYCLES: RHYTHMIC ACTIONS FOR ENGAGEMENT

This chapter describes findings¹ on the performance rate of repetitive actions frequently observed during interactions and interaction attempts in both studies. Observations made in early recording sessions prompted investigation of these repetitive movements. The aim of the analysis was: to map the temporal regularity of the movements; to define the contexts in which they arose; and to determine whether the same movements were performed at the same rates by the different groups of adults participating in the two studies (mothers, residential care staff, strangers who were experienced/inexperienced in working with people with profound mental handicap).

1. OBSERVATION AND ANALYSIS

1.1 Initial Observations

In the early stages of the research the adults were observed to use many repetitive movements involving physical contact to elicit and maintain communicative responses. Caregivers were frequently seen tapping, patting, stroking and manipulating the child's limbs and body. One caregiver with a blind child who had little independent movement constantly shook her arm, pausing only briefly to stroke her head or pat her body. This was very effective in gaining and keeping the child's attention and she responded with smiles, vocalisations and slight stirrings in her body, obviously enjoying the interpersonal contact. Another caregiver spent most of the time tapping, patting and stroking a child's limbs, face and mouth. It was clear that these were actions the child enjoyed and often initiated through his own movements. Another caregiver frequently shook a noisy toy very fast and quickly

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¹Preliminary findings were reported in: Burford, B. (1988) Action Cycles: Rhythmic actions for engagement with children and young adults with profound mental handicap. *European Journal of Special Needs Education*, 3 (4), 189-206. This chapter is based on the original paper and has maintained the original style where possible.

patted the child and objects he was holding, drawing his attention to the objects and to herself. When it was realised how often these actions were being observed during recordings, an examination of the available video records was made for further examples.

1.2 Analysis of Video Records

Analysis of video records was based on evidence obtained from detailed observations of video recordings using the same digital electronic time counter employed in Studies 1 and 2 and frame-by-frame analysis (with a frame advance of 40 milliseconds²). The purpose was to establish whether or not the observed actions, so obvious in the repertoires of several caregivers, were also present in the interactions with the other caregivers. Following on from this, it was sought to identify possible common features in the execution of these actions.

During the first stage of the investigation recordings of six caregivers from Study 1 were scanned, yielding many examples of patting, tapping, shaking and stroking. It was found that the actions were being performed in a repeated run or burst, with each action lasting between 120-360 milliseconds. The time band, i.e. the range of performance rates of each action, did not extend beyond 360 milliseconds (msecs) on any occasion. Examples of children performing similar actions were sought and, although occurring infrequently, they were found to be performing the same actions at similar rates. Similar actions were also observable in recording sessions for Study 2 and analysis of recordings of two caregivers, two experienced and two inexperienced strangers revealed that they, too, performed the same actions at similar rates. This was especially interesting since the two inexperienced strangers had had no previous experience with children with profound mental handicap and could not therefore be drawing from learned experience or from observing experienced caregivers.

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²Since this analysis was completed, digital video recorders allowing frame advance at 20 msecs per frame have become readily available. Analysis in this detail may enable the original categories and time bands to be even more tightly defined.

Having identified the possible existence of a collection of actions repeated in cycles at similar performance rates by different people, recordings which covered one session with each of the twelve caregivers from Study 1 were selected for a more detailed examination. As Study 2 data were still being collected at this time, a further sample of nine recordings of the four caregivers, four recordings of experienced strangers and four recordings of inexperienced strangers was selected from the video records then available.

Noting the performance rates of all repeated actions, the presence of other time bands containing slower rates was observed. It was found that actions such as stroking and patting were being performed at different rates on different occasions, although always at a regular rate within the one cycle of action. It was at this stage that the categorisation of actions was formalised. From there, the process was one of identifying and categorising further actions and examining the nature of the groups into which they appeared to fall. When all video recording was completed, further observations from both studies confirmed the initial findings.

A total of 2,758 action cycles were studied (caregivers - 2057; children with profound handicaps - 473; mothers of non-handicapped infants - 228). This was the number it was possible to examine within the time scale of the research: the sample does not contain all action cycles present in the video records.

2. RESULTS

2.1 Action Cycles

Analysis of the video records revealed rhythmic groups of cyclical movements which took the form of several kinds of deliberate actions easily distinguished from each other and from less specific movements made during interactions. These 'action cycles' were consistently used by adults to engage the child with profound mental handicap in interaction

or to maintain his or her involvement in an engagement. From the examples studied, it was clear that the cycles were brief, generally lasting under ten seconds and sometimes less than one second.

2.2 Forms of Action Cycles

A 'cycle' is an uninterrupted succession of similar actions: the actions contained within the cycle are complete movements in a sequence of similar repeated movements without pauses.

Adult

Possible action cycles included the following:-

1. The adult touches the child or manipulates his or her limbs - patting, tapping, poking, tickling, rubbing, nudging, stroking, shaking, swinging arms or legs, rocking, bouncing, jiggling, clapping.
2. The adult wiggles or waves her or his fingers, hands or tongue.
3. The adult waves, shakes or wiggles a toy.

Child

In seeking examples of similar behaviours on the part of the children, only actions observed during communication or attempts to communicate were included. For example, it was not considered an action cycle if a child sat rocking in a withdrawn state at a distance from the adult. On the other hand, if he or she began rocking in response to the adult or included the adult in his or her actions then this was categorised as an action cycle. Within communication, the rocking occurred in short bursts of action in response to what was happening between adult and child. When alone, a child would rock continuously for as long as he or she was left uninterrupted, the behaviour being persistent and unvaried and not reactive to communicative events.

Observed action cycles performed by the children included:-

1. The child touches the adult - patting, tapping, stroking with hands or fingers.
2. The child moves his or her limbs or whole body repeatedly - rocking, 'dancing'.
3. The child waves, shakes or wiggles a toy.

2.3 Categories

The action cycles were divided into five categories - Rapid, Moderated, Playful, Slowed and Soothing - according to the rate at which they were performed.

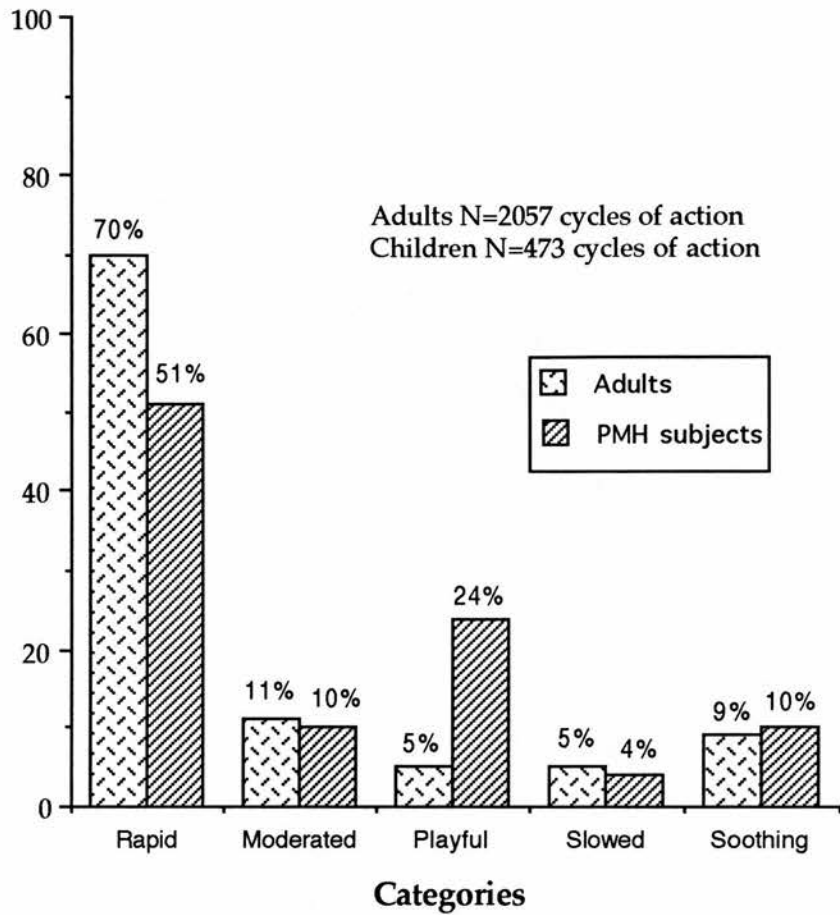
Actions were not exclusive to one particular category. Thus the stroking movement appeared at Rapid, Moderated, Slowed and Soothing rates, fulfilling different communicative or interpersonal purposes in each. The actions could appear very similar in form at the different rates, e.g. an adult stroking a child's cheek could perform one action very quickly (160 milliseconds) using a short stroke, or much more slowly (1,840 milliseconds) using a similar length of stroke. In the first example, the adult wished to elicit a lively communicative response whereas in the second example she or he wished to calm and reassure the child. The motive for the adult's choice could be inferred from what she or he was saying and doing, as in most cases adults provided a clear commentary on the child's behaviours, on what he or she might be thinking or trying to do and, in general, constructing a dialogue based around the child's movements and vocalisations. Table 9.1 presents the classification of action cycles.

The distribution of action cycles used by the adults and children is shown in Figure 9.1. Since the sample does not contain all the action cycles present in the video records, the selected examples may not reflect the true pattern of distribution. However, the pattern does confirm a strong impression gained by the researcher and the three raters that the very fast actions were by far the most prevalent. Support is further provided by Robertson's (1990) study in which he examined all action cycles within complete recordings of caregivers and children with profound multiple handicaps and found the majority to be Rapid actions.

Table 9.1 Action cycles classified according to performance rate

Category	Purpose
Rapid Action Cycles Rate: 120-360 msec. 208+ beats per minute (approx. Prestissimo and faster)	<p>Adults typically used Rapid action cycles to attract the child's attention, to elicit a communicative response or to maintain an interaction, and to express care and warmth in a lively way.</p> <p>Children used this to respond to the adult or to express enjoyment, by tapping, patting, stroking, and shaking a toy.</p>
Moderated Action Cycles Rate: 360-480 msec. 168-200 beats per minute (Presto - Allegro)	<p>Adults used this rate when the child was already responsive at a steady pace or to keep the level of excitement moderate and controlled, e.g. if a caregiver felt the child was tired or below par. It was still a fast rate but did not have the furious pace of the Rapid category.</p> <p>Children typically used this rate of action when involved in an interaction which had a moderate, evenly-paced level of excitement.</p>
Playful Action Cycles Rate: 480-720 msec. 78-108 beats per minute (Moderato - Andante)	<p>These rates were associated with mutual interpersonal contact through shared activities such as arm swinging or the adult waving a toy with the child 'dancing' in response.</p>
Slowed Action Cycles Rate: 720-1000 msec. 60-76 beats per minute (Adagio - Larghetto)	<p>Adults used this slower speed to gain or maintain interaction where the child appeared timid of social contact.</p> <p>Children used slowed actions to seek and reciprocate gentle, quiet contact with adults.</p>
Soothing Action Cycles Rate: 1000+ msec, often above 2000. 40 (and minus) beats per minute (Largo and slower)	<p>Adults appeared to pace their actions at this rate to express care and warmth, to relax and reassure the child.</p> <p>Children expressed relaxation and trust in the adult's presence through soothing actions.</p>

Figure 9.1
Percentage of Total Sample



Most of the actions observed were performed by adults, but eleven of the eighteen children were also observed to use such actions in all five categories, although the majority were Rapid or Playful. Where children performed actions similar to those of the adults, they did so with similar rates and regularity.

Though very infrequent, children did initiate the actions, most often in the Soothing category. On these occasions the child was signalling the adult to use soothing contact movements such as stroking, rather than the child soothing the adult. The adult had performed the action first and the child was requesting a repeat by guiding the adult's hand through the same action at precisely the same rate as had previously been used by the adult. Such instances were categorised as children's

actions since the adult was being prompted and led by the child. There were occurrences of mutual actions in which the participation of adult and child was shared and examples are described in section 3.5 (Mutual Contact and Action).

It is inevitable that the time taken to complete some actions was determined by the form of the action. If an adult swung a child's arms in as wide an arc as possible then a certain amount of time was required to complete the action, no matter how quickly it was performed. However, such actions seemed only to appear when they were fulfilling certain purposes and usually fell within the Playful category.

2.3.1 Rules for Measurement

The rate in milliseconds refers to the time taken to complete one action, e.g. one finger tap completed in 200 msecs. One action was part of a cycle of the same actions whose performance rates fluctuated only within a very narrow time band, e.g. the time band for Rapid actions was found to be 120 - 360 msecs. The actions within a cycle were performed continuously with no pause between each action. The start of the action was arbitrary and judged by a change of direction or using certain markers within a circular action, e.g. by the thumb passing a certain point as the hand moved round. On visually good video data the changes of direction were clear - unclear cycles, either too distant or partly obscured by subjects, were not included in the analysis.

It was important to gain samples from as many adults and children as possible. In addition, examples were sought from a variety of adults with the same young person in Study 2. People varied in the extent to which they used action cycles and, where someone used such actions infrequently, all visually clear examples were used, whether or not they formed a complete 'action cycle', e.g. sometimes the view of the end of a cycle was obscured when one of the participants changed position.

2.3.2 Reliability

Four hundred action cycles were included in the reliability sample, for which interrater agreement was high (98%)³. Three raters, all of whom worked with people with profound mental handicap, were given two half-day training periods during which they became familiar with the forms of action to be examined and gained experience in employing frame-by-frame analysis. The raters were asked to judge the beginning and ending of each action within the same cycle, e.g. the beginnings and endings of all ten actions within a cycle of ten continuous pats.

Each rater was given a list of time counter numbers indicating a point on the tape several seconds before the beginning of the first action in each cycle to be examined, along with a description of the actions to confirm identification of the example. They were asked to note the beginning and ending of the first complete action they observed once the tape began playing, e.g. the first 'pat'. They then noted the beginning and ending of each successive action within the same cycle until the cycle ended or became visually unclear. Each rater viewed examples from different recordings. The rater and researcher had to agree on the beginning and ending of an action within two frames (80 milliseconds).

2.4 Regularity of Rate

There was a striking regularity of rate within each performed cycle of actions. The regularity was more marked in the two fastest categories - Rapid and Moderated. There were minor fluctuations in rate but these rarely strayed outside the time band in which the action began, e.g. a cycle in which the first action began at a rate of 240 msec and continued within a range of 160 - 200 msec did not slow down unless the form of the action changed. Anomalies within a cycle of actions were explained by physical alterations, e.g. the adult shifted position, paused to speak or vocalise or changed the form of the action.

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³Calculated by: number of agreements, *divided* by number of agreements plus disagreements, and *multiplied* by 100.

2.5 Cross-cultural comparison with mother-infant interactions

The forms of action that caregivers were observed to use with children with profound mental handicap were also seen in recordings of mother-infant interactions. Using a sample of Trevarthen's⁴ video data, analysis of recording sessions of four Scottish and four Nigerian mothers with their 4-8 week-old babies found that the mothers were clapping, jiggling, patting, poking and tapping their babies at regular rates which fell into the two fastest categories - Rapid and Moderated. The cycles were short, none lasting more than a few seconds, and they showed a variety of forms of action.

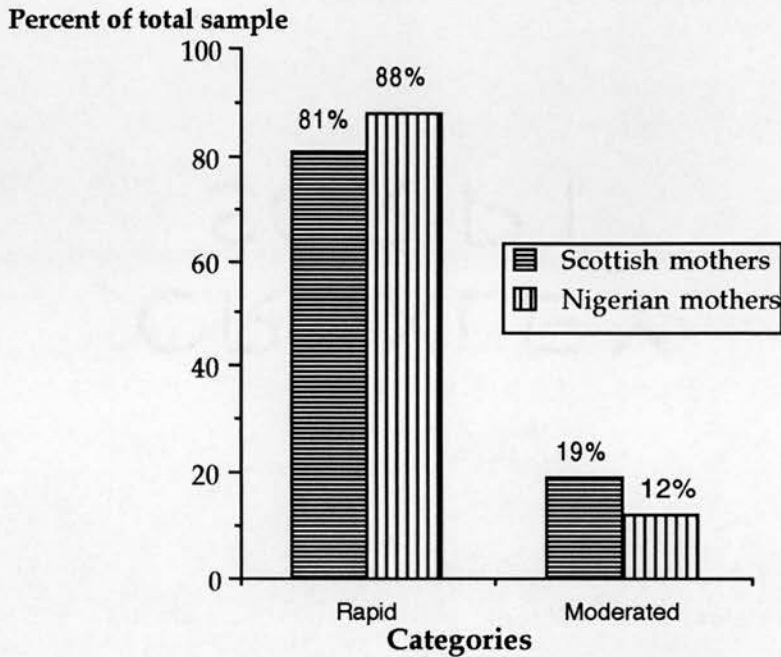
Video recordings by Burford of a Scottish mother and father with their baby at four weeks and eight weeks of age also revealed similar actions at the same rates. In these recordings each parent, on different occasions, also shook a toy in a similar way and at the same rate as that observed in caregivers with children with profound mental handicap.

The distribution of Rapid and Moderated action cycles for the Scottish and Nigerian mothers within the sample of observations is shown in Figure 9.2.

The absence of actions performed at other rates observed with the PMH subjects may be explained in a number of ways. The PMH and mother-infant studies both examined communication between a caregiver and a child, but the method of gathering video recordings was not controlled. The mother-infant recordings were chosen as visually clear examples of repetitive actions and they were not as large a sample as that obtained in the PMH studies.

Figure 9.2 Distribution of Action Cycles used by Scottish and Nigerian Mothers

Scottish N=92 cycles of action
Nigerian N=136 cycles of action



Cultural influences may also have guided the particular communicative behaviours by which a mother attempted to elicit responses from her baby - the Nigerian mothers worked especially hard to elicit smiles, showing a higher incidence of facial pinching, nudging and stroking. In addition, the very young age of the non-handicapped babies is likely to have had a bearing on the actions used by their mothers, especially with the four-week-old babies, e.g. they would not expect or seek the vigorous playful interactions that work well with a six-month-old baby (Trevvarthen, 1979).

In summary, comparisons of video records of interactions between Scottish and Nigerian parents and their non-handicapped infants yielded similar action cycles and rates to those seen in the interactions between children and young people with profound mental handicap and non-handicapped adult communication partners.

2.6 Action Cycles During Interactions: individual examples

Examining the rates allowed the common features among all participants to be identified, but it also revealed many stories about interactions which were taking place during fractions of a second, revealing a sensitivity in caregivers and children to each other's actions which was time-based.

2.6.1 Similar Rates for the Same Action amongst Different People

Example one - shaking a toy

The distribution of performance rates of ten different adults - 4 nurses, 3 parents, 2 inexperienced strangers, 1 experienced stranger and 1 child with profound mental handicap (Jane) - shaking the same toy using the same action is shown in Figure 9.3. The adults were all attempting to get a child's attention or to maintain his or her interest and excitement. Jane performed the action during a period of obvious enjoyment.

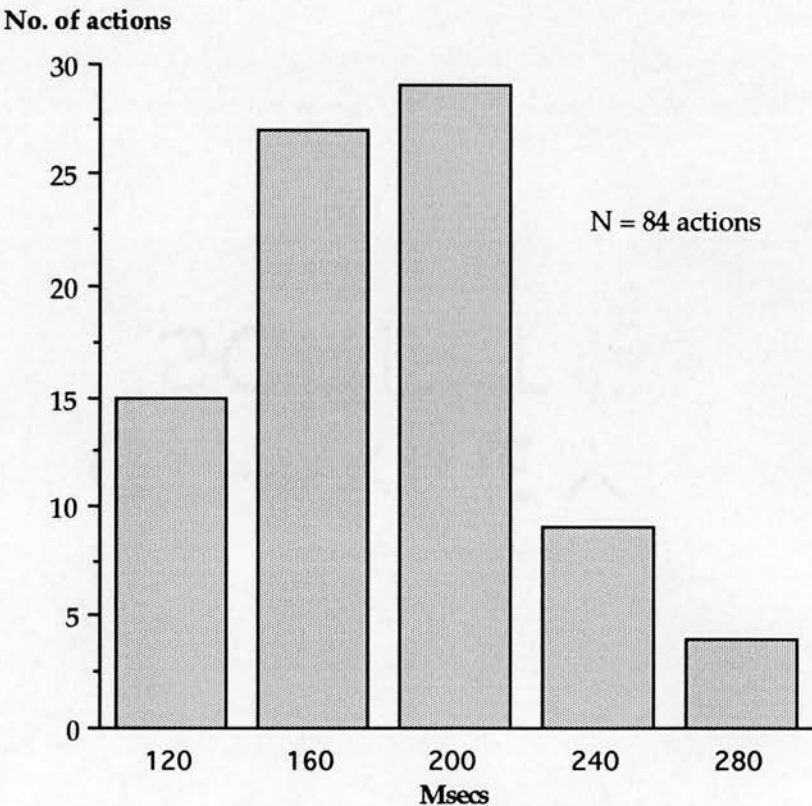


Fig. 9.3 The distribution of rates of actions used by ten adults and one child with PMH when shaking a toy

The action has been observed on many occasions and the rates of all those examined were found to be in the range of 120-280 msec, even if the adult shook the toy while the child was holding on to it. The toy was wooden with figures inside which rattled noisily. The same action was seen with other toys, e.g. a small squeaky turtle flapped in the air at a rate of 200 msec per flap. One young person with profound mental handicap, Michael, who was observed performing this activity with his caregiver was later observed initiating this action with a stranger, repeating the action cycles consistently within a narrow range of milliseconds.

Example two - adult taps child's lips with finger

Adults frequently tapped, stroked, poked and nudged the child's cheek, mouth, nose and chin with their fingers, usually in a series of short cycles, pausing to speak, vocalise or call the child's name in between.

Figure 9.4 shows the distribution of rates of tapping by five adults of five different children with profound mental handicap; one child (John) with profound mental handicap tapping the mouth of one of the adults, one mother with her non-handicapped eight-week-old baby, and two adult subjects tapping their own lips. John performed the tapping while exploring his caregiver's face as she made funny faces and sounds and stuck out her tongue, and later in the same session the caregiver tapped the John's lips and then her own. The other caregiver was tapping and stroking the child's face and lips, in the middle of which she tapped her own lips.

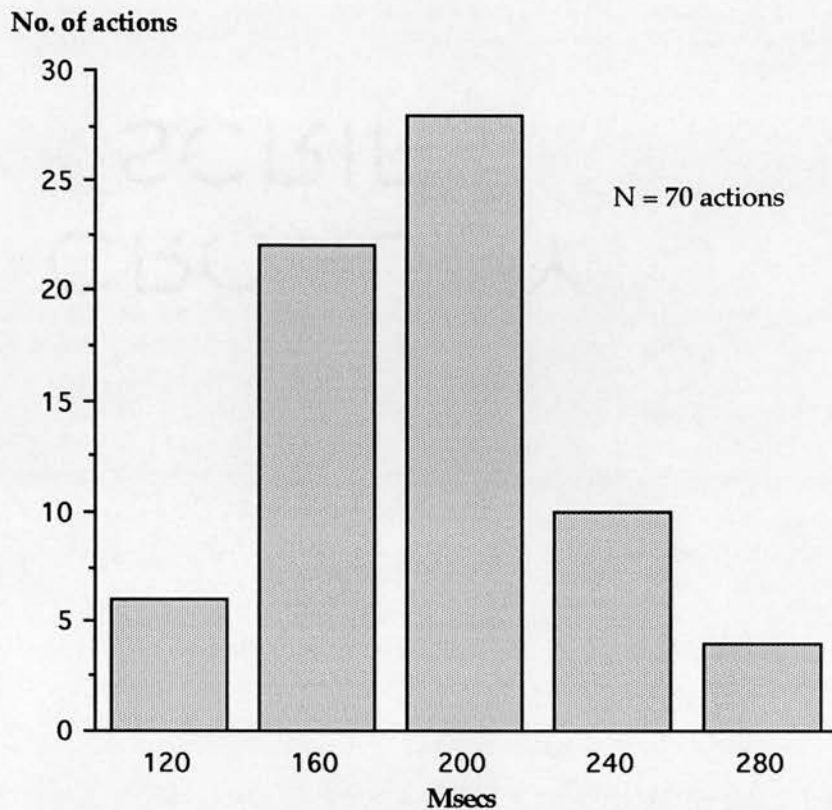


Figure 9.4. The distribution of rates of tapping by five adults and one child with PMH

2.6.2 The Influence of Micro-Timing during an Interaction

In one example an adult was sitting on the floor shaking a toy during a recording session with Terry. Terry responded by moving towards her and then joining in with another toy, both using Rapid actions. The adult paused for 0.52 seconds to watch Terry, then resumed shaking the toy. At one point in the cycle their actions began at precisely the same point. Terry finished his action 80 msecs after the adult and did not continue. The adult was now 80 msecs into her next action. Apparently sensitive to Terry's having stopped she stopped at the end of this action. Her reaction was within 120 msecs. She began shaking the toy again 440 msecs later with actions varying between 160 and 200 msecs. Terry watched, then took the toy from her and shook it at a steady rate of 200 msecs.

Millisecond analysis revealed relationships between actions which are hard to dismiss as coincidental. It suggests a careful monitoring by caregivers and children of each other's actions, although they themselves are unlikely to be consciously aware of these events, occurring as they do within a split second. In this case the caregiver appeared to react to an event in a faster time than the fastest possible reaction time of 180 msec. Stern (1977) believes that people are able to very quickly gain 'temporal' and 'spatial' maps of the other person through which they are able to anticipate the person's behavioural sequence, and this is demonstrated through their finely timed and co-ordinated behaviours.

2.6.3 The Same Action Performed at Different Rates

Example one

This example describes the action of rubbing a child's palm with a finger, performed at a different rate by two caregivers with two different children for different purposes. In one recording session the child, Linda, was already responding to and involved with the caregiver and liked physical contact. The action cycle was in the Rapid category, performed in the midst of many similar Rapid cycles such as patting. The caregiver kept up a constant flow of different Rapid action cycles to maintain the Linda's involvement. The duration of the cycle was 3.88 seconds.

In another session the adult was a stranger to the young person (Philip) and unfamiliar with people with mental handicap. Philip was wary of social contact and protected himself by withdrawing into himself and not responding to or acknowledging the other's presence. The adult was sensitive to this withdrawal and sat quietly near him, but making no demands on him. After a while she reached out and gently touched his hand which he accepted and their hands remained in contact. Philip began to relax, and the adult started to rub the his palm with her finger in a similar way to the caregiver in the previous example, but the length of action within the cycle varied between 880 and 960 msec, falling within the Slowed category. The duration of the cycle was 7.48 seconds, with the adult again sitting quietly by Philip when it ended. In the same

session Philip clapped his hands, though not in communication, in the Moderated range and the adult replied with hand clapping in the same range (360-480 msec). In a different recording session of Philip with his caregiver she was also observed to rub his palm within the Slowed category.

A later recording with an experienced stranger further demonstrated how sensitivity to Philip's preferred slow tempo could pay dividends. Near the beginning of the recording session Philip began rocking at a Soothing rate (the slowest category). The adult, who was sitting facing him, took hold of his hands and joined in, allowing him to pace the rocking. A few minutes later she re-introduced the rocking at the same Soothing rate of around 1700 msec per rock, eliciting smiles and quiet, 'happy' sounds from him. She initiated the rocking several more times and then began clapping her hands in short bursts at a Moderated rate, sometimes vocalising the beat. Philip joined in of his own volition with phrases of three or four hand claps, also at the Moderated rate. He appeared unusually relaxed and interested in the adult, perhaps resulting from her sensitivity to his need earlier in the session for gently-paced action.

Example two

It seems important for caregivers to perform the actions at a rate that suits the child and his mood. A rate that is too fast for one child can be too slow for another and there may be some actions that are interesting to a child only if performed at a certain rate. Mary, in two different recordings sessions with inexperienced strangers, got into her usual position of curling up over her knees on the floor, her forehead resting on the floor. She did not respond readily to others and her position made it difficult to establish interpersonal contact, especially for strangers unsure of whether to touch her and what to do and say. She had a habit of scratching the mat and patting it, actions which most adults copied as a way of trying to make contact. The first stranger patted the mat (Moderated category) and after a cycle of seven actions she paused; her next burst of actions were in the Rapid category, followed by a pause and then a return to Moderated cycles. She then rubbed the Mary's arm (Moderated) and a few seconds later scratched the mat (Rapid). Mary

looked towards the adult's hand during the Rapid cycles, but otherwise did not respond to her.

In a different recording session with Mary in the same position, another stranger drummed her fingers on the mat to try to gain her attention. The adult began in the Moderated category, paused, then continued this action and others in the Rapid category. This stranger gained Mary's attention more successfully than the previous one. Mary's caregiver was also observed to use similar Rapid actions and was the most successful in gaining her attention and making contact.

Caregivers were rarely observed to mismatch their rate with the children's needs and moods. Inexperienced strangers showed many more mismatches, but despite their complete lack of previous contact with people with such severe handicap they did manage to match up on many occasions.

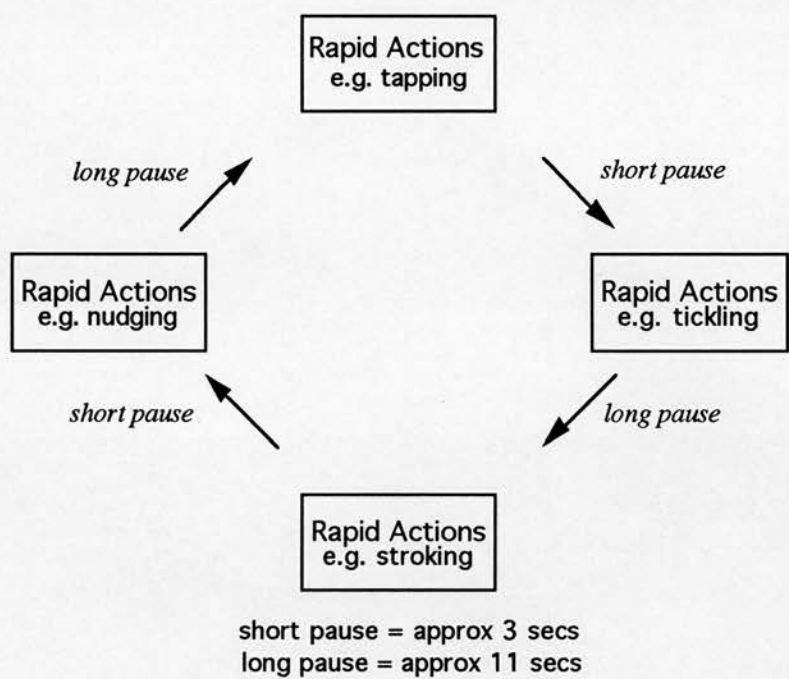
2.6.4 Maintaining a Flow of Different Actions at Regular Rates

In interactions with their infants, mothers are observed to use a variety of forms of action at a regular rate, thus maintaining a constant flow of cohesive activity (Stern, 1977). Similar features were observed in interpersonal encounters between caregivers and children with profound mental handicap. When they were seeking a response from the child caregivers often used frequent changes of action, all performed at similar rates.

In one example a caregiver, faced with Greig in an unresponsive mood, kept up a constant flow of different Rapid action cycles - shaking toys, tapping, stroking and tickling him. This was a very similar pattern to that of the Nigerian mothers eliciting smiles from their babies. She stroked Greig's cheek and chin or gently tapped the tip of his nose in short cycles, such as two stroking movement or three taps, pausing for varying lengths in between to say his name, lifting his head up, changing position to keep a clear view of his face.

During 53 seconds she fell into the pattern illustrated in Figure 9.5. In this way the caregiver kept up a constant flow of interaction attempts at a regular rate, interspersed with adjustments to her own or Greig's position to maintain optimal conditions for making interpersonal contact. From her many encounters with Greig she knew this was something which often produced a response. In this recording session she was not successful, but similar actions did produce communicative responses in all the other sessions - a point which highlights that careful note should be taken of what caregivers are doing even in the face of apparent lack of success.

Figure 9.5 Caregiver's flow of actions at regular rates



Caregivers often used a variety of action cycles in a short space of time, giving an appearance of constant change of activity, but sharing a similar tempo across the different action cycles and within the same cycle. For example, in a sequence initiated by Steven, a child with multiple handicaps, a caregiver was seen to expand on his initiating move with a variety of contact movements at a Rapid rate. The caregiver was leaning over Steven who was lying on a play mat, her hand resting on his chest. Steven patted the caregiver's hand with Rapid actions for 1.82 seconds. She immediately shook him playfully from side-to-side for 1.06 seconds, then stroked his head for 2.78 seconds. She paused for two seconds

calling his name, then patted his head for 1.88 seconds before zooming into his face and rubbing faces. Steven then hugged her before ending the interaction in his usual abrupt manner by pulling away. During this sequence Steven, who usually maintained little eye contact, looked intently at his caregiver's face, smiled and moved his limbs animatedly. He did not hug people often, but it was a feature of intense interactive moments with his caregiver, whose varied and continual use of Rapid actions seemed to evoke such moments.

Even actions which occurred infrequently in a caregiver's repertoire seemed to fit into the timing pattern. The few playful tugs by one caregiver to a child's T-shirt were even found to be performed at a rate of 200 msecs, in keeping with the continual taps, strokes and pats she had been using to keep his attention engaged.

2.6.5 Mutual Contact and Action

Shared rates of action between interactants help to pinpoint moments of mutual activity when the movements and body positions of both caregiver and child contribute to the whole activity. These co-active sequences of actions appear similar to the simultaneous vocalising between infant and mother that Schaffer, Collis and Parsons (1977) call 'chorusing' and Stern, Jaffe, Beebe and Bennett (1975) term 'co-action' - common feature of infant-caregiver communication which helps to cement interpersonal bonds and is more likely to occur as the participants become engaged in the interaction. This also applies to non-verbal expressions - the caregiver's simultaneous behaviour runs parallel to the infant's behaviour rather than injecting her responses into the infant's turn, so that they are 'acting together' (Trevvarthen, 1977).

Example one

The episode began when the child, Mark, snuggled against the caregiver, comfortably moulded into the shape of the caregiver's body with his head resting against the caregiver's lap. The caregiver was sitting gently tapping, tickling, rubbing and patting Mark using Rapid action cycles.

Mark initiated many of the actions by raising a limb to be tapped or guiding the adult's hands to pat him. The caregiver then made palm-to-palm contact with him and they began mutual hand stroking, each drawing his hand down the other's palm and away, then moving the hand forward again to regain contact. Two cycles, at very slow rates in the Soothing category, were performed within seconds of each other - the first at a regular rate of 2.84 seconds per action (of the actions we were able to see sufficiently clearly). The second cycle fluctuated more but was still regular - 3 seconds, 2.8 seconds, 2.6 seconds, 2.08 seconds, 2.04 seconds. It was a mutual activity with a regular beat which appeared to be agreed and adhered to through non-verbal channels and from the moment the actions began.

Example two

In a second example with Mark, his caregiver made contact with the Mark's outstretched hand and a waving action initiated by the caregiver began. Mark was an active participant, having to keep his hand stretched up to meet the caregiver's hand. The cycle was performed at a Rapid rate of action and lasted 1.44 seconds.

Later the caregiver was playing with Mark's hand, patting and rubbing it. This became a brief, mutual pat performed as a Rapid cycle. Several minutes later the caregiver and Mark again patted hands in the same way.

These mutual action cycles occurred within a period of eight minutes and formed part of a series of different action cycles in which the caregiver initiated the mutual hand wave, stroked Mark's head, played with his hands (which led to the mutual hand patting), rubbed the his back, swung his arms and moved them in a circular motion, rubbed his back again, shook his body in play, patted his foot, and then patted the child's head leading up to a second period of mutual hand patting.

Within eight minutes Mark and his caregiver had three episodes of sharing an enjoyed activity whose purpose was interpersonal contact. It

had been encouraged and supported by a range of actions performed by the caregiver at regular rates, mainly within the Rapid category.

Example three

In a session with an inexperienced stranger and Sean the stranger picked up a toy and shook it with a Rapid action. He held it out to the Sean who took it and also shook it at a Rapid rate. At the same time the adult mimicked Sean's action at precisely the same rate, creating a form of sharing through the mime and its tempo.

Example four

In one episode lasting just over seven seconds Robert initiated an interaction with his caregiver by reaching across with his right hand and patting her upturned left hand. During his first seven pats she held her hand steady and then began joining in with the patting from underneath his hand. She began patting Robert's left hand in the same way, after her first two pats with her right hand. Robert was not looking at his caregiver but they managed to achieve a remarkable closeness in their rates (see Figures 9.6a and 9.6b), ensuring that they unerringly made contact on each pat. The caregiver finished patting with both hands, one pat before Robert also finished.

Robert was a quiet, withdrawn young person who rarely looked at others and appeared not to be aware of their actions or presence, yet he was capable of initiating and maintaining his participation in a mutual communicative action.

Figure 9.6a

A comparison of rates of patting between a child with PMH and his caregiver

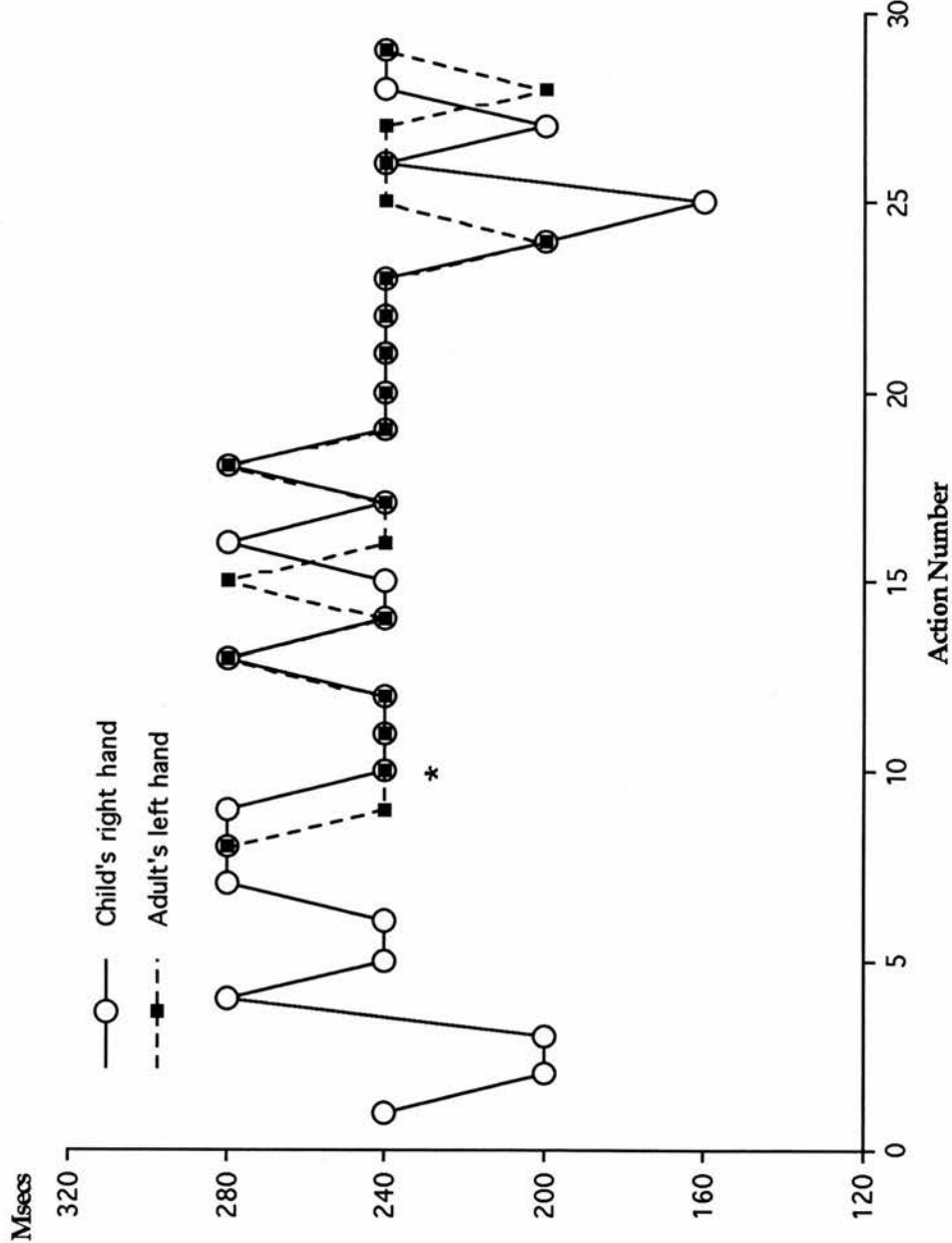
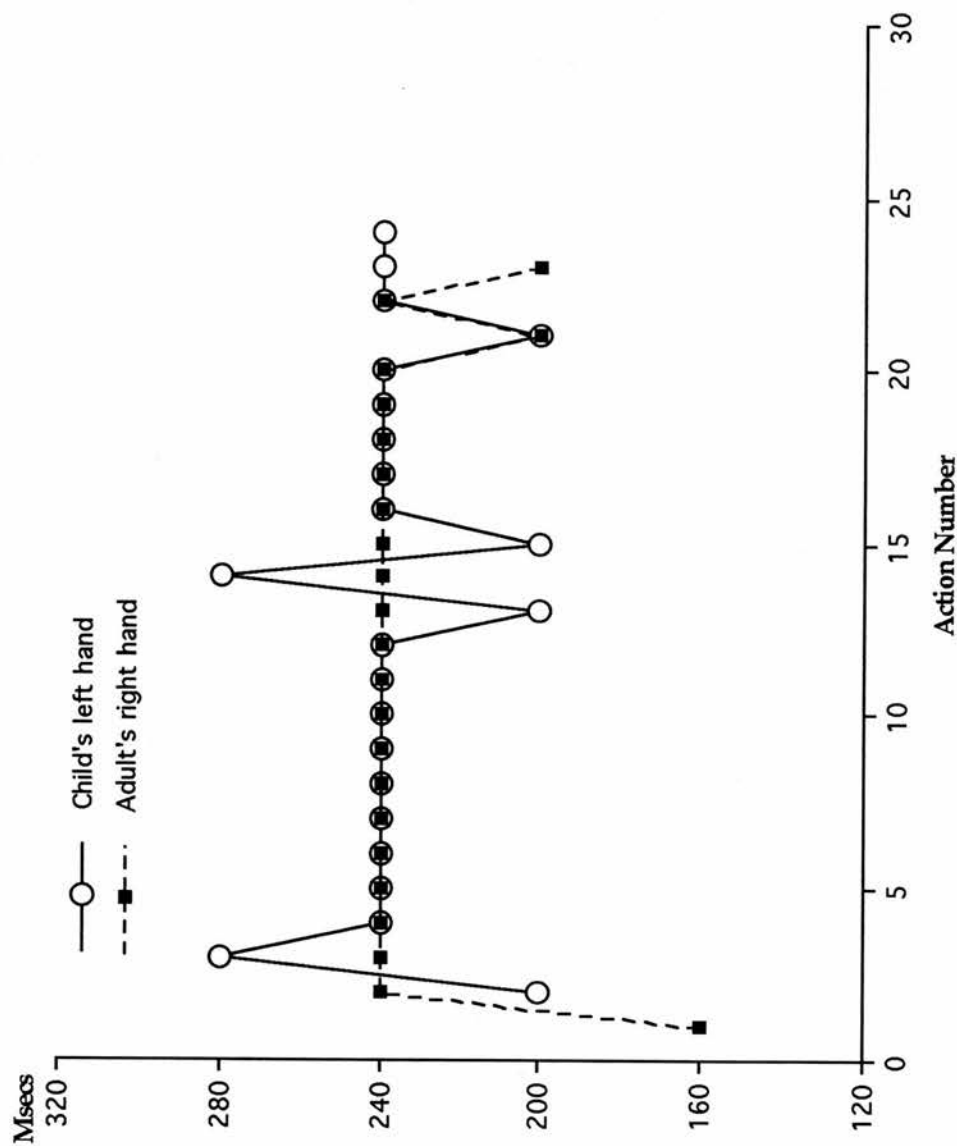


Figure 9.6b Adult begins patting with her right hand



As the child's right hand and adult's left hand go down,
the child's left hand and adult's right hand move up.

2.6.6 Regularity of Rate of Playful Action Cycles Performed by Children with Profound Mental Handicap

Example one

This example concerns Michael who enjoyed shaking a teddy up and down in both hands, with arms extended. He was performing cycles of action within the Playful category, usually ranging from 520 to 640 msec per action. In one sequence he performed a cycle of eleven actions, each action deemed to start when he moved his arms down. The first ten actions lasted 600 msec each, with the final one being completed in 560 msec. As Michael completed an action he moved his arms forward exactly two frames (80 msec) each time before beginning the downward stroke. Each action was different in shape, some finishing lower than others and some forward strokes varying in length - but he always took the same time to complete an action and to move his arms forward. The forward movements seemed to allow him to regulate the cycle, producing a very regular rate despite the changes in the shape of the movement. In later recordings his caregiver was seen to use this rate when playing with the teddy in the same way, Michael responding with laughs, body movements and sometimes vocalising in time with the action. An inexperienced stranger who performed a similar shaking action, but at a very slow rate of 1400 msec, failed to maintain Michael's interest in the action.

Example two

Greig who had gross physical deformities and very restricted movement responded to his caregiver's waving a squeaky toy as if he was dancing to music, moving his limbs and body in a side-to-side motion as he lay on his back. His movements looked awkward and jerky, yet the cycles of action revealed very regular rates within the Playful category. A further example of this precision was demonstrated by Steven who took his caregiver's hand to his mouth and patted it against his lips at a Rapid rate. His caregiver then carried on the patting on her own at this same rate, much to Steven's enjoyment.

It is remarkable that children with profound mental and multiple handicaps who perform very poorly on known tests of motor skill and

development can achieve such control over their expressive actions. Perhaps the answer lies in the fact that the actions had enjoyment and meaning for the children and had arisen from inner motivation that was reinforced by interpersonal contact.

3. DISCUSSION

3.1 Temporal Patterns in Human Communication

We sometimes lack appreciation of the common features of human behaviour, not realising the significance of their organisation, purpose and ubiquity. Newson and Newson (1975) refer to this when describing the rhythmic co-ordinations permeating human behaviour, saying that it is probably because of their pervasiveness that they have been taken for granted and their presence in infant behaviour has been overlooked. Bateson (1979) remarks how we have considered the success of mothers in soothing their babies by jiggling and tapping them to be self-evident and that it is only in recent years that such behaviours have become the object of intensive study.

This could similarly apply to the behaviours of caregivers and children with profound mental handicap. It is so easy to accept that something observed frequently and which is done with ease is effective, without considering *why* it works. Caregivers of children with profound mental handicap have many obstacles to overcome to establish communication and build a relationship. It makes sense that the strategies and behaviours we see them use are those which are the most successful. If caregivers who are in daily contact with a child continually do something, then we should ask *why* this is happening and why *these* behaviours. At the beginning of the investigation caregiver behaviours that were occurring frequently were excluded because they often occurred at times other than during periods of direct interaction. It became obvious, however, that the behaviours were being used as communicative strategies.

The results showed that the performance rates of these behaviours fall into a pattern determined by communicative purpose and offer evidence of similarity with patterns of physical contact movements observed in early interactions with non-handicapped babies. Research in developmental psychology into the tempos of mother-infant communication behaviours substantiates the suggestion that non-handicapped infants and children with profound mental handicap share the same basic framework for communication: the action cycle categories appear similar to the temporal patterns which typify early communication in normal development. The narrowness of the time bands for each category and the minor fluctuations in rate occurring within these bands also appear to be typical characteristics of human temporal patterning. Stern et al (1975) state that human behaviour characteristically unfolds at fluctuating rates, but within defined limits and with predictable tempos.

3.2 Tempos in Mother-Infant Communication

The split-second world of mother-infant communication operates on an absolute time scale. Within this scale adults and babies are able to anticipate the fall of the next beat with great accuracy and to detect tiny alterations in the regularity of the beat (Campbell, 1986). Trevarthen (1986a) concludes that communication movements are based on a brain-generated common absolute time base which transcends cultural influences and learning, such a base providing a fundamental part of the mechanism that enables the infant and mother to interact. The expressive movements which arise spontaneously during these interactions are formed round a beat with a range of tempos which are universally used by adults (Trevarthen, 1986a), an example of this universality being found in studies of nursery songs in many different cultures and languages which reveal an andante beat (76 - 108 beats per minute, around 1 beat per 790 - 560 msecs) (Trevarthen, 1990).

Trevarthen (1990) has found that protoconversations with infants have a slow beat, generally adagio, which is approximately 66-76 beats per minute (around 1 beat per 910-790 msecs). Mothers use exaggeration,

repetition and a slow tempo compared to adult conversations (Schaffer, 1977) and have longer pauses (Stern et al, 1975). Tronick and Adamson (1980) found that mothers who were asked to slow down their speech while talking to their babies evoked delighted and attentive responses.

The potency and versatility of the tempos used by mothers to communicate with their infants is reported by a number of researchers. Infant interactions are conducted within a very narrow range of time which seems designer-made for their primitive nonverbal communication. Mothers usually clap, rock and sing to their babies with a tempo rarely slower than *adagio* or faster than *presto* (Beebe, Stern and Jaffe, 1979), all the behaviours being contained within a spectrum of around 66-200 beats per minute. Beebe (1982) calls this the 'magic range', the time frame of the infant's social world. It enables the baby to anticipate the beat and predict the timing of the mother's behaviour (Campbell, 1986) and seems designed to maximise the infant's attention and involvement (Fernald, 1985).

The regular beat of communication behaviours provides a cohesive framework for inter-linking tempos, e.g. a mother can use patting and jiggling movements at a fast rate, nested within a protoconversational phrase, proceeding from phrase to phrase at the slower beat of protoconversations. Although the range of tempos is narrow, mother and baby can perform a wide variety of communication dances to many permutations of the 'magic range' of beats. Stern and Gibbon (1980) suggest that changes in the timing of the mother's behaviours play a pivotal role in affective communication, the modality used by the caregiver to stimulate the infant seeming less crucial than its temporal patterning (Stern et al, 1975).

3.3 Tempos in Children with Profound Mental Handicap

The rates of action during which the adult and child appeared most likely to be mutually engaged and reciprocating ranged from Moderated to Slowed, this being especially true of the Moderated and Playful categories. Adults appeared to use the very fast and very slow rates

(Rapid and Soothing) more usually as strategies for prompting communication, maintaining the child's involvement or level of arousal, or for calming and reassuring the child.

In a study of interactions between four children, aged 7-17 years, with profound mental and multiple handicaps and familiar and unfamiliar caregivers, Robertson (1990) found that the adults used active physical contact movements for the majority of the session. Many of these actions were highly regular and performed with precise timings which fell into the action cycle categories, the majority being Rapid or Moderated actions. Robertson analysed all the actions used by the caregivers and found that a portion, 16%, did overlap boundaries between adjacent categories, e.g. Rapid/Moderated. Nevertheless, none leap-frogged into categories further removed, e.g. Rapid/Playful. The purposes appeared similar to those found in this study - Rapid actions were used to elicit and maintain interactions and Soothing actions to reassure and relax the child.

The action cycle range of tempos are shown to be comparable to the range observed in infant communication, as illustrated in Table 9.2. This suggests a possibility that, in common with parent-infant communication, the rate of movement in the presto-adagio range (moderated-slowed) is generally used for play and reciprocation. The very fast and very slow rates appear to be used more often as communication strategies, the former used principally for raising the state of arousal and capturing attention and the latter being a way of responding sympathetically to vulnerable emotional states.

Paradoxically, caregivers in the PMH studies were sometimes observed using a very *fast* rate for soothing and calming children, but this too has parallels in mother-infant communication. Similar rapid behaviours are sometimes used by mothers to console an agitated and upset infant and, in fact, this can be seen between adults in similar circumstances. Trevarthen (1986a) gives an example of a mother calming a distressed infant in which she patted the infant at a rate of 3-4 pats per second, between 250-330 milliseconds per pat. Rapid behaviours such as these have the appearance of 'nipping trouble in the bud', attempting to

override and calm the build-up of agitation and upset (Stern, 1977). Stern describes how a mother will soothe an over-excited infant by speeding up her speech or movement to override the baby's fussing, then slow her behaviours down as the baby quietens.

Table 9.2 Tempos observed in infant communication

Tempo	Purpose
Presto Around 200 beats per minute (Rapid)	Mothers use this tempo to calm infants, e.g. patting (Trevarthen)
Andante 76-108 beats per minute (Moderated)	The beat of nursery songs in different cultures and languages (Trevarthen)
Presto - Adagio 66 - 200 beats per minute (Rapid - Playful)	Mothers' communication behaviours contained within this range - the 'magic range' of infant communication (Beebe, Stern, Jaffe)
Adagio 66 - 76 beats per minute (Slowed)	Protoconversations have a slow beat . (Schaffer; Trevarthen; Tronick) Rocking at this rate is seen to immediately calm babies (Morris) ⁵

⁵See Chapter 3, Section 3.2, discussion on heartbeat as pacemaker.

3.4 Sensitivity to the Beat

Although the temporal beat provides predictability, variations in tempo can also produce a varied social stimuli. In mother-infant interactions the mother's behaviours follow a regular tempo which she usually maintains within an interaction, but she might change tempo from one interaction to the next (Stern, 1977). The mother varies the emphasis of her behaviours and their breadth and intensity as she goes along, giving the impression of constant flux. Her array of behaviours, designed to stimulate and capture the baby's attention and involvement, are made cohesive by a common tempo. Mothers are observed to manipulate the beat interval in anticipatory games. Stern (1977) describes the way in which a mother will play games such as "I'm gonna get you." She elongates the beat interval between each successive phrase, creating a discrepancy between the infant's expectation of when the first beat of the next phrase will fall and when it actually does, thus generating excitement in the baby. Such anticipation is a remarkable feat and Stern suggests that the baby must have a very finely-tuned timing system which can operate within fractions of a second.

Perhaps even more remarkably, children with profound mental handicap also seem to be sensitive to micro-timing. Earlier examples described how children with profound mental handicap were extremely sensitive to tiny variations in tempo, e.g. a child reacting differently to tapping performed at a rate of two hundred milliseconds per tap, compared to tapping at a rate of 400 milliseconds.

3.5 Summary

Universals of infant communication are well documented, with the timing factor identified as a crucial element in the regulation of rates of communicative movements and co-ordination of expressive behaviours. The regularity of pace assists in holding the structure of episodes of communication together. Interactions are reactive to the events of the moment and are full of unpredictability, and social

encounters would be chaotic if they did not have some regulatory feature. Campbell (1986) describes human communication as rather like a musical improvisation with those taking part behaving like musicians. Each person's responses create the melody while the regularity of the beat supplies a much-needed predictability and cohesiveness, holding the interaction together.

This might appear discouraging when we turn our attention to the child with profound mental handicap whose movements can so often be severely affected by physical and sensory handicaps in a way that appears to preclude the possibility of any co-ordination of movements with others. The findings suggest that children with profound mental handicap and their caregivers do share a common beat in the movements they use during interactions. The presence of these actions indicates that a biological basis for responding to and participating in interpersonal exchanges exists in people with profound mental handicap, giving them a robust capacity for participating in emotional communication, which can quite literally be tapped into by caregivers. The finding of the same actions at the same rates in interactions between Scottish and Nigerian parents and their non-handicapped infants lends further support to this hypothesis.

The split-second world of infant communication operates within a range of tempos similar to the action cycle range. The analysis appears to have uncovered a range of tempos for communication between adults and children with profound mental handicap which is part and parcel of human communication rather than a phenomenon driven by their handicaps. The sensitivity of the subjects with profound mental handicap to temporal changes and mismatches reveals a capacity to detect and anticipate tempos which have been found to play a pivotal role in affective communication between non-handicapped infant and caregiver. The research offers evidence that this is also true for children and young people with profound mental handicaps.

The first stage in the analysis has been the observation and description of events, providing information to enable further examination of the action cycles repeatedly observed in the recordings of interactions with

people with profound mental handicap. The information gathered from this study forms a useful basis for further examination of the temporal regularities of the actions. Within the time scale of the study it was not possible to conduct further analysis, but the search for other possible forms of action cycles needs to be continued and the rates of the slower cycles need to be defined with greater precision. New computer and video technology which has become available since the completion of the study should greatly reduce the laborious nature of the transcriptions and assist in an even more precise analysis of performance rates.

It would be interesting to explore the link between emotional states and the performance rates suggested by these results. Greater understanding of the underlying psychological processes would help to further describe the part these rates of action play in interpersonal communication.

1. STUDY 1

1.1 The Structure and Order of Communication

Each child appeared to have a 'communication menu' for responding during episodes of interaction. Physical and sensory handicaps determined the menu to some extent, but children with similar disabilities did not have identical 'menus'. One child's body movements might signify communication, whereas in another child, similar body movements have no such significance.

The children's behaviours are not expressed haphazardly. They occur within an ordered pattern that showed remarkable consistency, supplying the caregiver with a stability and predictability, which seems to be an intrinsic part of the structure of human communication. The strikingly regular pattern of behaviours, sometimes in both interaction and non-interaction episodes, gives the caregiver a clear frame of reference for identifying moments of communication. Order and repetitiveness are also seen in the caregivers' behaviours, providing the children with a predictable communication partner. The exchanges were coactive, in keeping with observations of exchanges between mothers and infants. Turn-taking exchanges were observed only very infrequently in any of the unedited video recordings.

In recordings of mothers with their non-handicapped babies, mothers' comments reveal what they think about the baby's attention and level of interest and arousal (Trevvarthen, 1988). The caregivers' comments to the children in Study 1 provided similar information about what they thought of the child's interest and attention. In the non-communication episodes they frequently commented on and gave reasons for the child's lack of response, e.g. "are you not speaking to me?", "Oh, you're tired, aren't you?" In the communication episodes they typically made remarks such as "you're a chatterbox today."

Bridger (1964) investigated whether 2-5 day-old infants differed in their ability to be soothed when distressed. He found consistent individual differences in the infants' soothability, with some being soothed more effectively by certain of the stimuli used in his study. For example, he found one infant was soothed by a sound, another by rocking and another by sucking a pacifier. He states that it is likely that similar maternal behaviour will have different effects on different babies and that the behaviour of the neonate may partly determine the mother's behaviour. Bridger concludes that child-rearing practices should be adjusted to suit the individual qualities of each child.

Mothers describe the personalities of their children to be consistent from early infancy, this being borne out by longitudinal recordings of a number of children over the first three years. For example, although all two-month olds are seen to react to their mother's withdrawal of communication, their individual reactions differed from withdrawal to anger (Murray, 1980). There is a "common code of affect" in infants (Murray, 1980), but with an individual stamp, just as mothers have individual ways of communicating and caring for infants.

Stern (1977) describes how interactions between the mother and her non-handicapped infant are based on continual improvisation in which the 'steps and notes' have never been written down. There will be similarities between all mothers, but each mother and baby will also show differences unique to their partnership. Innate social responses develop into a joint 'communication system' that is subtle and sensitive to individual idiosyncrasies (Bruner, 1983). This would also seem true for children with profound mental handicap and their caregivers, but it should also be emphasised that, unlike interactions with non-handicapped infants, the caregivers have to work extremely hard to activate the communication system.

1.2 The Importance of Social Context

Microanalysis of human interactions, though laborious and time-consuming, yields rich data that tells much about the structure and the

nature of the communication. Birdwhistell (1970) makes the important point that these selected segments should always be finally examined within context. Indeed, much relevant information about the events within the communicative segments would be lost without reference to the backdrop to the communication. Most importantly, the behaviours of one communication partner should be viewed within the context of the other partner's behaviours. People make many adjustments to each other's presence without explicitly focusing on each other, and during shared activities a person picks up information from the other's movements and the timing of his or her actions and speech (Rogoff, 1990). The micro-timing within which the caregiver and child conducted their exchanges was remarkable. The child's and caregiver's behaviours were closely coordinated, giving a dance-like quality that was particularly striking when viewed in slow motion. This information would be lost if the behaviours of one partner were studied in isolation from the other.

This type of information supplies an important piece of the communication jigsaw. For example, there are many reasons why a caregiver responds in a certain way and it helps to view his or her behaviours in relation to the child's actions. In one engagement a child was seen to be very responsive and smiled a lot. However, the caregiver was not smiling. Was she being insensitive and unresponsive? Examination of her behaviour in relation to the child's actions revealed that she was indeed being *very* sensitive. She was holding her head still so that the child could 'hit' her. Her main task was not to smile back, but to ensure the child's success at hitting her. He succeeded, and she protested "oh, you're hitting me, ouch!", making him laugh. It is a game they play frequently, part of their play ritual. The child's smiles expressed his enjoyment, they were not directed *at* the adult. She concentrated on 'stage-managing' his success. Smiling back at him was not the most crucial part of that particular encounter.

1.3 Observing and Acting on Spontaneous Actions

It is important to emphasise that the interactions between the children and their caregivers arose from the children's spontaneous actions. There was no pre-planned script in which their idiosyncratic forms of expressing likes

and dislikes, or of requesting a favourite game were determined or imposed by someone else.

Many such actions are not intentionally made, but they can sometimes become intentional if an adult acts on them as if they had specific meaning. Some actions may be very clear, such as raising an arm to be tickled, but others may be more obscure, such as holding the body in a certain posture. Caregivers become very adept observers of these forms of action, noticing tiny details, as demonstrated by the mother who noticed that her daughter flared her nostrils when attending to others.

By acting on these observations in a consistent way the adult can sometimes help the person with profound handicap to become aware that his or her actions can have an effect on others and that as well as responding, he or she can initiate and direct what will happen. It does seem, from talking to parents and teachers, that once a child has gained this awareness it is generally robust and can be generalised to other people and other situations. The child may lose interest in the original activities and cease using the actions associated with it, but he or she continues to develop other specific means of directing and requesting specific events. He or she retains the knowledge that what he or she does can influence other people and will apply this knowledge to new interests. This is, in fact, a very important development for the child with profound mental handicap, showing evidence of goal-directed behaviour (Stage IV in Piaget's sensorimotor period) and offers an observable measure for assessing different levels of attainment within this group of children. Caregivers may be an important source of information in identifying the child's idiosyncratic actions and their possible meaning. Yet again, the pivotal role of the caregiver is highlighted.

1.4 Biobehavioural States

During the recording sessions caregivers appeared very sensitive to the children's changes of mood and alertness and frequently commented on these. Many caregivers in the study remarked on the effect the time of day had on the child's level of alertness. Recordings sessions were sometimes

timetabled to accommodate a child's state changes. In Latchford's study, many caregivers reported dips and peaks in their child's state of arousal, and not all of these conformed to the usual day/night pattern (Latchford, 1989).

The study of biobehavioural states promises to be an interesting development in the field of profound mental handicap. Not surprisingly, perhaps, this too originated from research with non-handicapped infants. Papousek and Papousek (1988) have observed that infants display individually different and regular changes in biobehavioural states and suggest that the role of biobehavioural states in social interactions might offer a useful guide in timing the intervention of caretaking activities, e.g. feeding.

Richards and Sternberg (1992) conducted a pilot study with a group of school students with profound mental handicap, which examined the effect of a range of environmental variables (such as student 'alone' or 'with staff') on their biobehavioural states. The latter were defined by orienting responses based on eye focus and eye movements. The students were found to orient more often when staff were close or touching them, supporting the suggestion that orienting does have communicative significance for this group. Richards and Sternberg suggest that systematic observation of the students' states of alertness and their attempts to interact and express emotions is a fruitful area of research. A number of variables used by Papousek and Papousek, e.g. head movements, head turns and vocal sounds, could be appropriately applied to people with profound mental handicap, thus allowing blind students (excluded from the study by Richards and Sternberg) to be included.

1.5 The Caregiver-Child Partnership

When with a responsive caregiver the children demonstrate very similar communicative capacities to non-handicapped infants, using facial, body and vocal behaviours in interpersonal contact. During an interaction, the caregiver watched the child's reactions very closely and adapted her or his behaviours to suit the child. Both male and female caregivers participated in the study and not all were parents. This suggests that these behaviours

are not exclusive to female parents nor confined to those with parental experience, lending support to the suggestion that the processes involved underlie a basic form of human communication.

In early infancy, long before the development of symbolic understanding, a rich and varied communication between infant and mother can be observed, which takes place through their non-representational actions and expressions. Interactions between children with profound mental handicap and their caregivers appear to be based on similar forms and tempos. Given the extensive brain damage suffered by many of these children, the similarity suggests that these processes are biologically robust and form a crucial aspect of human development: one that children with profound mental handicap have highlighted through their communicative capacities and the ordered structure of their communication of children.

The results of this study suggest that the normal development of affective communication does offer an appropriate model for understanding the development of interactions in children with profound mental handicap. This model can offer guidance on effective ways of encouraging the fullest possible development of the capacities the children do have for interpersonal contact, providing a sound basis for the development of therapy and intervention procedures appropriate to the child's developmental level. However, great care must be taken to ensure that clear distinctions are made between the 'model' and the intervention practices it informs. A particular therapy or method of intervention may provide an environment in which interactive processes can be effectively activated. It is important to remember that the processes themselves are biologically-based and do not originate from therapeutic procedures. They cannot be claimed as the sole domain of any one particular technique. Most important of all, it should not be forgotten that it will often be the 'untrained' caregiver who is the most skilful and sensitive 'practitioner'.

Future research

The methodology used to study mother-infant interactions proved to be well-suited to studying interactions in children with profound mental handicap. The study has provided evidence of similarities in the structure of basic person-to-person interactions between normally developing infants and the population with profound mental handicap. However, within a few months the interactions of the non-handicapped infant rapidly become more complex and sophisticated, following a sequence of development that progresses in an unvarying order. During the analyses of interactions in Study 1 it was clear that there were differences in the amount and the complexity of the responses shown by the children, but it was outwith the scope of the research to follow this line of enquiry. It would be interesting to find out whether a progression of sequential development exists in the interactions of children with profound mental handicap and whether this has similarities with the normal course of development. Hodapp et al (1990) state that:

“examination of retarded and otherwise disabled groups provide rigorous tests of issues such as the presence of universal sequences of development and of unified stages of development across domains (p21).”

Thus, this line of enquiry may offer further insights into processes of psychological development in children with profound mental handicap and non-handicapped infants.

There is a major drawback to research of this nature. In the study the detailed transcription and analyses of video records was extremely time-consuming and laborious, and reliability checks demanded a generous donation of time from raters. Arising from this experience, a computerised system of video analysis¹ is currently being developed at the University of Edinburgh by Dr. Hamish Macleod and the author to enable speedier and more efficient transcriptions.

2. STUDY 2

2.1 Comparisons between Adult Groups

The differences in the amount and depth of contact achieved by the three adult groups strongly suggest that the young people do discriminate between those they know and strangers, and that personal relationships with caregivers and the previous experience of strangers play an important part in encouraging communication. The findings showed that it is possible to generalise previous knowledge about other people with similar mental handicap to a new person very quickly during the first meeting, so that some kind of social contact can be made.

2.1.1 *Caregivers*

The CG group had a history of communication which had developed from their many interpersonal encounters over a period of years and were familiar with the young people's moods, likes and dislikes and their usual ways of responding and making their wishes known. They reported that most of their day-to-day encounters arose spontaneously during moments such as dressing and mealtimes, but there were also times when they had longer episodes of play and communication. The caregivers considered it important to spend time playing and chatting with the young people, just being with them with no set goals, but that this could not be rigidly planned or imposed - the young person had to be 'in the right mood' and 'feel like taking part.'

The caregivers used the young person's actions and sounds as the basis for communication, building on whatever he or she was doing at the time, or introducing events the young person was known to enjoy, e.g. making a favourite noise. They used toys inventively and play was rarely conventional. During sessions, physical contact between young person and caregiver was evident in a wide variety of forms. The CG's kept close to the young person and frequently adjusted their position to keep level with him or her, even if this meant crouching down, kneeling or lying on the floor. They adjusted their pace to suit the young person, bombarding him or her

with activities if this approach worked best, or slowing the pace down and sitting quietly alongside if a gentle approach was preferred. They moved round the room with the young person, rather than remaining on the spot and watching.

Even in the relatively short period of recording and analysis it could be seen that the nature of the exchanges between the caregiver and young person did not remain static and that surprising capacities could be revealed. In Michael's games with his caregiver, he showed a concentration and understanding that was at odds with his usual performance. His fine motor control was poor and he did not copy the actions of others. Several attempts to teach him to use some Makaton signs for play activities he enjoyed had proved unsuccessful. He measured very poorly on known assessment scales, with his highest level of achievement, motor development, being assessed at an eighteen-month level of development. Yet, in one game which appeared for the first time during the recording period, he showed that he was able to differentiate between two very similar actions: one in which he placed his right index finger on his caregiver's lips and another in which he placed the palm of his hand flat on her face, each sign indicating different facial games. These signs had a meaning for Michael that was gained within the context of the many play rituals that were a significant part of their communicative exchanges.

The CG group showed their relationships with the young people do have an advantageous effect on the young person's responses and participation. The two caregivers who were partnered with two subjects did not behave in the same way with each and did not elicit similar patterns of response. This suggests that the exchanges observed between caregivers and young people were based on dynamic partnerships that are shaped by the young person's needs and responses.

2.1.2 Experienced Strangers

The young people showed greater involvement with the experienced strangers compared with the inexperienced group. However, there was no significant difference in time they spent in reciprocal engagements and it

can be seen that differences between the two groups of strangers emerged most strongly in the Passive Involvement and Active Involvement categories. In addition, the profiles of the individual PMH subjects show that most adults in the ES group tailored their approach to the needs of the individual. In the sessions they tried out ideas based on their previous experience with similar young people and they were prepared to break social rules, especially those involving physical contact. They quickly discarded approaches that did not work and concentrated on those that did elicit a response. They were more tentative than caregivers about using physical contact until they had had time to gain an impression of the young person. From their experience, they were aware that physical contact was important, but also knew that not all young people could readily tolerate being close to someone else, especially a stranger.

The ES adults played with toys in a similar way to the caregivers and were often aware that the young person had expectations of play in a certain way, though they could not always guess what form the play should take. This was reflected in their speech, e.g. "what do you want?", "what is it you want me to do?" Sometimes they did guess successfully, an achievement which reflects how effectively the young people can communicate their needs to adults who are sensitive to their basic mode of communication.

The ES group found their previous experience to be generally helpful, although two adults in this group did employ strategies with Michael and Terry which backfired. They held back from intervention, aiming to give the young people an opportunity to show what they wanted to do and to avoid making them anxious by imposing too much. They both greeted the young people warmly, introduced themselves and then sat down and watched them, commenting from time-to-time on whatever they were doing. Both Michael and Terry showed an initial interest in the adults, but then withdrew and amused themselves in the ways they usually did when left to their own devices: Michael spent his time laughing and squealing, running round the room in circles, picking up toys, waving them in the air and flinging them across the room; Terry moved to the other side of the room and played with a favourite toy, his fingers in one ear, laughing to himself and paying no attention to the adult. The adults lack of intervention inhibited the young people's initial interest in their presence. These

examples suggest that there is a need to balance choice and autonomy with essential intervention.

The ES group seemed to be at the same disadvantage as strangers with non-handicapped infants. They did not have the historical knowledge that evolves within regular interpersonal encounters and were unable to decipher the young person's idiosyncratic actions. Generally though, the experienced strangers showed the aspects of their previous experience which were the most helpful in establishing some form of effective communication within the initial minutes. They found their previous experience particularly helpful with Philip and Robert, the two young people who were withdrawn, and least effective with Michael and Sean who had specific expectations of how the adults should respond and participate.

2.1.3 Inexperienced Strangers

The young people's sessions with the IS group were characterised by impersonal conversation, minimal physical contact, conventional forms of play and a goal-oriented approach. They made (one-sided) small talk, e.g. comments on the room, weather, or the young person's bright clothes, rather than weaving a conversation of words and sounds round whatever he or she was doing, as the ES and CG groups were observed to do. They often held the young person's hand, but were tentative about other forms of contact, especially active contact such as patting. They kept at the social distance normally observed between adult strangers in the UK, rarely moving as close to the young person as the other two adult groups. They mostly sat or stood watching when the young person roamed around the room, rather than moving round with him. They concentrated on toys most of the time, using them in a conventional way.

The IS group focused on tangible goals, trying to persuade the young person into specific actions, e.g. to catch a ball, to sit down, or to play with a toy. Much of their intervention was devoted to pursuing these aims and, unlike the ES group, they persisted with an ineffective approach rather than changing tactics. It was obvious to many IS adults that they were having

little success, but they had no idea of how to proceed differently. Their experience was akin to being in a strange new culture, unable to speak the language or make sense of the customs. Shanley (1986) describes how the first encounter that new staff have with residents in institutions for people who are mentally handicapped can result in 'culture shock'. They are propelled into a world that breaks many of the rules about touching, looking at and being close to other people, making it difficult for the newcomer to know how to respond. Many of these behaviours are threatening or very intimate within our society, but do not carry the same meanings within the institution (Shanley, 1986). The IS group were immediately exposed to a marked form of culture shock; most had no previous encounters with people with *any* degree of mental handicap and were entering the recording room within the first hour of their visit to the hospital. Their medical training offered them no guidance in coping with such a direct personal encounter and many reported a feeling of being 'de-skilled.'

One recording session with Philip provides a stark example of difficulties the IS group encountered:

The adult appeared immediately put off when Philip ignored her greeting and her offer of a toy. He sat in a chair opposite from her for a while, appearing relaxed but uninterested in what she was doing. He then moved across the room to stand leaning against the radiator, playing with his string and completely ignoring the adult, neither looking in her direction nor giving physical cues that he was aware of her presence. She sat watching him in silence for several minutes, making no attempt to attract his attention. Then she too 'switched off', fidgeting and looking aimlessly round the room. Eventually she turned her back on Philip and fiddled with a toy, staring into space and showing signs of discomfort. It became clear that nothing further was going to happen and the session was stopped after six minutes².

The adult's comments after the session are interesting. Although she was forewarned in the introductory remarks about the difficulties of people with profound mental handicap she was very taken aback to have her greetings completely ignored. She found his silence and stillness very off-putting and

²It was important that the inexperienced strangers were given positive comments about their meetings with the PMH subjects. The adult participated in a teaching and discussion session immediately after the session. During the video review there was an opportunity to emphasise that Philip's lack of response was a typical feature of his encounters with strangers and not a personal reaction to this particular adult. The ways in which Philip did communicate and how this usually developed were described, emphasising that this always needed time to develop.

had no idea of how she could attract his attention. When Philip moved away from her she gave up, feeling rejected and angry that he was not responding. She felt he was incapable of responding and that further efforts were pointless. The adult's comments gave an insight into the very personal effect that the young people's unresponsiveness can have and the strong feelings that rejection can arouse. Several inexperienced strangers commented on a strong feeling of rejection when their approaches were ignored, especially if there was a clear sign such as a young person turning his back on the adult. In the normal course of communication, walking away, turning your back, looking through someone, staring blankly in response to a smile, or ignoring an outstretched hand can send powerful and very personal messages of rejection. The ES and CG groups had encountered many such rejections from people with profound mental handicap and were able to put them in context, aware that they did not carry the personal significance normally associated with such behaviour.

2.1.4 The Effects of Familiarity and Experience

The ES group were able to use skills developed through their previous experience to make some form of social contact and were more able to develop the contact further than naive strangers. The results indicate that previous experience can be very helpful in achieving some form of immediate social contact in new encounters, but that the relationship between the person with profound mental handicap and the adult plays an important part in developing the deeper communication.

The ES adults showed aspects of their previous experience which were most helpful in establishing some form of communication within the initial moments of meeting. For example, it does not appear to interest the young people much if toys are used in a conventional way. Experienced strangers often effectively incorporated physical contact, e.g. walking a squeaky toy up the young person's arm as it is squeaked rather than relying on the sound alone to attract attention. The IS group usually tried to attract attention by conventional play with toys and this was generally unsuccessful. The adults' behaviours were shown to have a strong influence on the amount of involvement with the young people, supporting the view

that working in partnership with them rather than 'getting them to do things' is a more fruitful approach. With this population the key to success lies in the adult's actions rather than his or her speech content.

2.2 Physical Contact

Close proximity and some form of touch play a prominent part in many interactions with the young people. It is interesting to note that all the young people received some form of physical contact from each group of adults, suggesting that even naive strangers were responding to a sense of basic communication. The closeness and physical contact used by the caregivers and many experienced strangers would have been inappropriate with non-handicapped young people of the same age. In the UK such behaviour normally denotes intimacy, thus powerful social and cultural rules have to be overridden to establish successful communication with the young person with profound mental handicap. It can be seen from the individual profiles that the form of physical contact is not haphazard, but is governed by the young person's preferences - the amount he/she will tolerate, the form he/she prefers. Physical contact is not simply a form of comforting, although it might be used at times to soothe and reassure, but a dynamic channel of communication.

2.3 The Importance of Personal Relationships

The results of Study 2 show that observing young people with profound mental handicap in communication with someone they know well can be an effective way of obtaining a comprehensive picture of their communicative capacities. One young person's communication can be the same as another's except for one minor detail, but it may be a detail that makes a crucial difference to the success of the communication. A familiar figure is well-placed to detect these differences and elude the capacities the young people do possess. For example, one person may respond to having her hand held gently, but pull away from more active contact such as patting, whereas another increases her response when her hand is patted and jiggled.

There can be many variations of an apparently similar event: they cannot all be considered as one single event if we want to gain a full picture of the individual young person's different ways of communicating and responding. An event in which a young person initiates a game with hands after an adult has taken hold of his hand cannot be classified as being exactly the same as a young person taking hold of an adult's hand out-of-the-blue to start the hand game. The latter is an autonomous act, while the former has a degree of dependency on the first move being made by the adult. Splitting hairs in this way may seem very trivial in the normal course

of everyday communication, but in communication with people with profound mental handicap it can be crucial in achieving a response. Not all the young people will give the more readily recognisable signs of acknowledgement and co-operation, e.g. looking, smiling, and so this type of detail might be the main source of information. It is clear that it is important to pay close attention to the individual styles of communicating, capitalising on the young person's preferences and gradually encouraging a greater range of responses.

The unit staff participating in this project had very good personal relationships with the young people. It is not possible to state how typical this unit was of institutions in general, but the results highlight that the staff within an institution are its most important resource; effective communication depends on empathic communication partners.

The degree to which people with profound mental handicap form attachments is not easy to ascertain and the methodology was not suitable for examining this important topic in either of the two studies. Strangers can be offered the same warm welcome as a family member, and family members can be kept at the same distance as strangers. Fear of strangers is rarely evident in the way demonstrated by a non-handicapped baby, but some children with profound mental handicap are fearful of people in general, cautious even of familiar figures. However, this is more likely to be a symptom of their pathology rather than evidence of a 'stranger-effect'. Nevertheless, some children with profound mental handicap do seem to show evidence of attachments, though not as marked or intense as those of non-handicapped infants (Latchford, 1989).

Nevertheless, the results give an insight into the power of personal relationships; the responsibilities such relationships place on the non-handicapped partner; the capacity that young people with profound mental handicap have for differentiating between familiar people and strangers; and the crucial part that the adult's actions play in fostering such communication. Though techniques can be employed to improve the lines of communication, the power of the relationship itself should not be forgotten. Communication is more than achieving a set of skills - it is about taking one's place in the world of humans where there is a shared emotional understanding between individuals. Communicative exchanges provide an effective means of expressing love, hate, frustration, anger, happiness, sadness and for providing an understanding that these expressions are noticed and understood by other human beings. They are a fundamental part of human life.

There are many things beyond the grasp of young people with profound mental handicap. They are totally dependent on others for their basic needs and personal survival, but it is very clear that communication with other people is well within their grasp and that they can form and enjoy relationships of differing quality and intensity. The relationship between the adult and young person makes a difference to the young person's responses, as does the previous experience of strangers in working with similar young people. Decisions about residential placements, relocation within residential units and any change which involves losing familiar people and adapting to strangers should take into account the existing relationships enjoyed by the young person, the effect of losing these familiar figures and the initial effects of unfamiliar caregivers in new placements. Most importantly, the communication should be viewed as a partnership in which young person and caregiver work together - it is a shared experience. The young person supplies the spark; the adult partner ignites it.

3. CAREGIVER REVIEWS

In both studies, the caregivers provided an insight into aspects of the child's responses which only day-to-day personal contact can reveal. Bakeman and Gottman (1986) refer to people with experience in the field of investigation as 'cultural informants' and this is an apt term for caregivers. They understand the communication channels open to the child and the odd ways in which they sometime communicated.

Newson (1981) has used parents as an important resource for many years at the Child Development Research Unit at Nottingham University. She says:

"We start from the basic assumption that parents in fact have information to impart: that parents are experts on their own children. This is not to say that what they know of their children is in any systematic or integrated form: one cannot ask the parent to bring along to the clinic an ordered case-history of the child.....the fact that their knowledge may be diffuse and unstructured does not matter, so long as it is available. It is the professional's job to make sure that it is available: structuring can come later (Newson, 1981, p170)."

Yoder (1986) suggests that parents have a unique form of knowledge. In his studies, mothers of children with severe handicaps appeared able to identify subtle cues in their infant's responses not noticed by others, including the research team.

As Newson makes so clear, the important aim should be to make the information available: to provide insight and encouragement to parents of a particular child, to offer guidance and support to parents as a group, and to provide information to professionals that only someone who knows the child intimately can provide. Referring to work with parents of babies with Down's syndrome, Cunningham (1983) sets the scene for an equal working partnership between parents and professionals: parents develop an expert knowledge of their child through their daily contact, while professionals gain expertise and a wide knowledge of development through contact with many babies. In this way, parent and professional can pool their resources and work together (Cunningham, 1983).

Schlesinger (1987) highlights the potency of the feelings of success that caregivers experience when an infant participates in mutual interactions with age-appropriate behaviours. A caregiver can accommodate some

limitations in the infant's responses, but experiences a sense of failure with an unresponsive infant or one whose responses are scrambled and difficult to understand. An infant's inability to respond can engulf the caregiver in a negative cycle of failure, helplessness and despondency (Scheslinger, 1987). Support for the caregiver-child partnership is essential.

The video reviews in both studies highlighted the training potential offered by the procedure itself. Many caregivers commented that they found it useful, and enjoyable, to be able to sit down and look at what their child was doing with an 'outside eye'. Video is an excellent medium for teaching and explaining how movements, facial expressions and eyes can be used to communicate and in showing how speed and rhythm of movement can play a part in communicating with others. It can also show very clearly how each person's actions can affect the other. Information can be shared with and demonstrated to all those who come into contact with the child, increasing the likelihood of children receiving consistent and empathic responses to their actions from a wider variety of people.

Newson (1981) also found that video was an effective way of offering support to parents, giving them an opportunity to stand back and gain a new perspective on their child. SPIN³, a Dutch organisation, have developed an effective approach called 'video home training'. Video feedback from videos taken in the family home are used to help parents and children communicate more effectively and pleasurably. The home trainers have found the benefits from this approach to be effective, rapid and long-lasting. It is capable of assisting in the resolution of severe problems in family communication and relationships, and has been used to help parents of children with mental handicap to recognise and make sense of the child's communicative actions. A wide range of professionals (nurses, health professionals, social workers) have been trained to use this approach, cutting across professional divides. The training emphasises the importance of allowing parents to retain responsibility for their child: the professionals offer support and guidance but do not tell the parents what to do. A video of this approach in action with parents in a hospital paediatric unit (van Rees, 1992) demonstrates that the use of video feedback is a practical and supportive approach for helping parents.

In both studies a vast untapped wealth of caregivers' knowledge about the child's communication was revealed, although the caregivers were themselves unaware of their own expertise. Parental information often remains hidden from the public eye; it is difficult to describe, never easy to demonstrate on cue, and the forms it takes may seem odd by conventional standards of communication. Parents are at a particular disadvantage in describing how they encourage their child to communicate and in providing evidence to confirm their observations that their child is indeed capable of communicating.

Professionals who are involved in developing communication with people with profound mental handicap can work within the framework of their profession's practice and theoretical base. It is less easy for parents to do this. Their first encounter with someone with profound mental handicap is usually with the birth of their child. They are not ready-armed with a theoretical base and range of techniques to help them understand and tackle the problem. They do not have the terminology available to professions to describe events and have little opportunity to view their child's responses in relation to other children with profound mental handicap. Some may be part of a self-help group or association within which common viewpoints are formed that influence what the parent does and provide some form of common support. However, this is entirely dependent on living in an accessible location which is also fortunate to have such a group. Many parents live in isolation from parents of other children with profound mental handicap and have little chance to compare notes.

Future research

In collaboration with Dr Hamish Macleod, the author has recently begun a research project involving children with profound mental handicap and their parents, based on the methodology developed for the caregiver video reviews in Studies 1 and 2. Using video recordings of the children during their usual daily routine, the research aims to investigate and document parents' knowledge of their own child and bring this into the public eye. It proposes to find out what parts of their child's behaviour tells them when he or she begins and finishes communicating and the judgements they make of the child's level of involvement during these episodes. Other parents

who have a child with profound mental handicap and professionals will also review each recording in the same way. In this way a wide picture will be provided - from parents and professionals - of the ways in which the children communicate and make themselves understood. In the same project, analysis of the nonverbal behaviours of children and parents is being conducted to identify possible key criteria for identifying episodes of communication, building on the observations and experience gained from Study 1 and the Action Cycle research described in Chapter eight.

4. CONCLUDING COMMENTS

Piaget showed that infants were able to acquire the basic elements of practical reasoning before they developed symbolic thought and language. He believed that the infant constructed representations through the manipulation of objects and that the pattern of affective development coincides with the developmental pattern of the stages of the object concept. However, the evidence from mother-infant research suggests that the infant is able to perceive persons and participate in affective interactions before he or she has mastered the manipulation of objects (Bloom, 1990). Trevarthen and his colleagues (e.g. Trevarthen and Hubley, 1978) have found that infants are able to comprehend emotions in other people and use emotional expressions to regulate affective interactions in a highly elaborate way before they have mastered the manipulation of objects.

The findings of Studies 1 and 2 show that children and young people with profound mental handicap, who provided little evidence of cognitive functioning, were able to participate in interpersonal contact, and that the young people in Study 2 differentiated between familiar and unfamiliar communication partners. Latchford's (1989) findings with children and adults with profound mental handicap offers similar evidence. Both sets of findings lend support to the belief that the emotional and cognitive systems are separate: emotional communication and expression is not dependent upon cognitive functioning.

Studies 1 and 2 revealed that, beneath the apparent chaos and disorder in the behaviours of children with profound mental handicap, an ordered

system of emotional communication is operating, similar in basic form to the communication observed between mothers and their non-handicapped infants. In the normal course of development higher level processes such as language develop and extend this foundation, but these basic structures appear to remain at the core of all human communication (Trevvarthen, 1986a). This suggestion is supported by comparative studies of adult-adult and mother-infant interactions which provide strong evidence that these interactive processes are a fundamental part of human social behaviour (Capella, 1981).

Non-handicapped infants and their mothers provide a model for gaining a greater understanding, and respect, for the communication between children with profound mental handicap and their caregivers. However, the gains are not only in one direction: children with profound mental handicap provide evidence of the robustness of the structures of basic communication. The durability of basic communicative processes in children and young people with such severe forms of handicap suggests that the basic forms of emotional communication play a vital role in human life, regardless of intellectual ability or physical capacity.

BIBLIOGRAPHY

- Ainsworth, M.D.S. (1982) Attachment: Retrospect and prospect. In C.M. Parkes and J. Stevenson-Hinde (eds) **The Place of Attachment in Human Behaviour**. London: Tavistock Publications Ltd.
- Ainsworth, M.D.S., Blehar, M., Waters, E. and Wall, S. (1978) **Patterns of attachment: A psychological study of the strange situation**. Hillsdale, N.J.: Lawrence Erlbaum Associates.
- Allport Gordon, W. and Vernon, Philip E. (1933) **Studies in Expressive Movement**. New York: The MacMillan Company.
- American Psychiatric Association (1987) **Diagnostic and Statistical Manual of Mental Disorders**. Washington, DC: American Psychiatric Association. 3rd edition.
- Bakeman, R. and Gottman, J. (1986) **Observing Interaction. An introduction to sequential analysis**. Cambridge: Cambridge University Press.
- Bates, E., Begnini, L., Bretherton, I. and Volterra, V. (1977) From gestures to first words: on cognitive and social prerequisites. In M. Lewis and L.A. Rosenblum (eds) **Interaction, Conversation and the Development of Language**. New York: John Wiley.
- Bateson, M.C. (1979) The epigenesis of conversational interaction: A personal account of research development. In M. Bullowa (ed) **Before Speech: The Beginnings of Interpersonal Communication**. Cambridge: Cambridge University Press.
- Bavelas, J.B., Black, A., Lemery, C.R. and Mullett, J. (1985) Motor mimicry as primitive empathy. In N. Eisenberg and J Strayer (eds) **Empathy and its Development**. Cambridge: Cambridge University Press.
- Bax, M. (1991) Editorial, "Family Matters". **Developmental Medicine and Child Neurology**, 33, 1035-1036.
- Beebe, B. (1982) Micro-Timing in Mother-Infant Communication. In M.R. Key (ed) **Nonverbal Communication Today**. New York: Mouton Publishers.
- Beebe, B. and Jaffe, J. (1992) Mother-infant vocal dialogues. In Tiffany M. Field (Special Editor) **Infant Behavior and Development**, 15, Abstracts Issue, Eighth International Conference on Infants Studies, Florida. Norwood, N. J.: Ablex Publishing Corporation.

- Beebe, B., Stern, D. and Jaffe, J. (1979) **The Kinesic Rhythms of Mother-Infant Interactions.** In Aaron W. Siegman and Stanley Feldstein (eds) **Of Speech and Time: Temporal Speech Patterns in Interpersonal Contexts.** Hillsdale, N.J.: Lawrence Erlbaum Associates.
- Beebe, B., Jaffe, J., Feldstein, S. and Alston, K.M.D. (1985) **Interpersonal Timing: The Application of an Adult Dialogue Model to Mother-Infant Vocal and Kinesic Interactions.** In T.M. Field and N.A. Fox (eds) **Social Perception in Infants.** New Jersey: Ablex Publishing Company.
- Berg, J.M., Clarke, A. and Clarke, A.D.B. (1985) **The changing outlook.** In A.M. Clarke, A.D.B. Clarke and J.M. Berg (eds) **Mental Deficiency. The changing outlook.** London: Methuen and Co. Ltd. 4th edition.
- Birdwhistell, R.L. (1970) **Kinesics and Context.** Philadelphia: University of Pennsylvania Press.
- Blacher, J. (1984) **A dynamic perspective on the impact of a severely handicapped child on the family.** In J. Blacher (ed) **Severely Handicapped Young Children and their Families.** London: Academic Press.
- Bloom, Lois (1990) **Developments in Expression: Affect and Speech.** In N.L. Stein, B. Leventhal and T. Trabasso (eds) **Psychological and Biological Approaches to Emotion.** Hillsdale, N.J.: Lawrence Erlbaum Associates.
- Bosmajian, Haig A. (1971) **The Rhetoric of Nonverbal Communication.** Glenview, Illinois: Scott, Foresman and Company.
- Bowlby, J. (1969) **Attachment and Loss, Vol 1.** New York: Basic Books.
- Brackbill, Y., Adams, G., Crowell, D.H. and Gray, M.L. (1966) **Arousal level in neonates and preschool children under continuous auditory stimulation.** *Journal Experimental Child Psychology*, 4, 178-188.
- Bretherton, I. and Ainsworth, M.D.S. (1974) **Responses of one-year-olds to a stranger in a strange situation.** In M. Lewis and L.A. Rosenblum (eds) **The Origins of Fear.** New York: Wiley.
- Bretherton, I., McNew, S. and Beeghly-Smith, M. (1981) **Early Person Knowledge as expressed in gestural and verbal communication: when do infants acquire a 'theory of mind'.** In M.E. Lamb and L.R. Sherrod (eds) **Infant Social Cognition.** Hillsdale, N.J.: Lawrence Erlbaum Associates.

- Bridger, Wagner W. (1964) **Individual Differences in Behavior and Autonomic Activity in Newborn Infants**. Paper presented at the 92nd meeting of the American Public Health Association, New York City.
- Browning, M.M., Bailey, I.J. and Clarke, O. (1981) **Schools and Units for Profoundly Mentally Handicapped Children in the Strathclyde Region of Scotland**. Glasgow: Jordanhill College of Education.
- Bruner, J. (1974) From Communication to Language - A Psychological Perspective. *Cognition*, 3, 255-287.
- Bruner, J. (1975) The ontogenesis of speech acts. *Journal of Child Language*, 2, 1-19.
- Bruner, J. (1983) **Child's Talk. Learning to Use Language**. New York: W.W. Norton and Company.
- Buck, R. (1981) The evolution and development of emotion expression and communication. In Sharon S. Brehm, Saul M. Kassin and Frederick X. Gibbons (eds) **Developmental Social Psychology**. Oxford: Oxford University Press.
- Buck, R. (1982) Spontaneous and symbolic nonverbal behaviour and the ontogeny of communication. In R.S. Feldman (ed) **Development of Nonverbal Behaviour in Children**. New York: Springer-Verlag.
- Buck, R. (1983) Nonverbal Receiving Ability. In John M. Wiemann and Randall P. Harrison (eds) **Nonverbal Interaction**. Beverly Hills; London: Sage Publications.
- Buck, R. (1984) **The Communication of Emotion**. New York: The Guildford Press.
- Bullowa, M. (1975) When infant and adult communicate how do they synchronise their behaviours? In A. Kendon, R. Harris and M. Key (eds) **Organisation of Behavior in Face-to-Face Interaction**. The Hague: Mouton Publishers.
- Bullowa, M. (1979) Prelinguistic communication: a field for scientific research. In M. Bullowa (ed) **Before Speech: The Beginnings of Interpersonal Communication**. Cambridge: Cambridge University Press.
- Byers, Paul. (1979) Biological rhythms as information channels in interpersonal communication behavior. In S. Weitz (ed) **Nonverbal Communication**. Oxford: Oxford University Press.

- Cairns, Robert B. (1977) *Beyond Social Attachment*. In Thomas Alloway, Patricia Pliner and Lester Krames (eds) *Advances in the Study of Communication and Affect. Volume 3. Attachment Behavior*. New York: Plenum Press.
- Cameron, Jo and Sturge-Moore, Leonie. (1990) *Ordinary, Everyday Families. Action for Families and Their Young Children with Special Needs, Disabilities and Learning Difficulties*. Under Fives Project, Mencap London Division.
- Campbell, J. (1986) *Winston Churchill's Afternoon Nap. A wide-awake enquiry into the human nature of time*. London: Paladin Grafton Books.
- Capella, J. (1981) Mutual influence in expressive behavior: Adult-adult and infant-adult dyadic interaction. *Psychological Bulletin*, 89, 101-132.
- Carr, J. (1984) Family Processes and Parent Involvement. In J. Dobbing, A.D.B. Clarke, J.A. Corbett, J. Hogg and R.O. Robinson (eds) *Scientific Studies in Mental Retardation*. London: The Royal Society of Medicine and the MacMillan Press Ltd.
- Chapple, E.D. and Coon, C.S. (1942) *Principles of Anthropology*. New York: Henry Holt and Company
- Christie, P. and Wimpory, D. (1986) Recent research into the development of communicative competence and its implications for the teaching of autistic children. *Communication*, 20 (1), 4-7.
- Clark, Gere N. and Seifer, Ronald. (1983) Facilitating Mother-Infant Communication: A Treatment Model for High-Risk and Developmentally-Delayed Infants. *Infant Mental Health Journal*, 4 (2), 67-82.
- Cleland, C.C. (1979) *The Profoundly Mentally Handicapped*. New Jersey: Prentice-Hall.
- Clements, John. (1987) *Severe Learning Disability and Psychological Handicap*. Chichester: John Wiley and Sons.
- Cromer, R.F. (1984) Comments on chapter by Kiernan 'The Development of Communication and Cognition'. In J. Dobbing, A.D.B. Clarke, J.A. Corbett, J. Hogg and R.O. Robinson (eds) *Scientific Studies in Mental Retardation*. London: The Royal Society of Medicine and the MacMillan Press Ltd.

- Comer, Ronald J. (1992) **Abnormal Psychology**. New York: W.H. Freeman and Company.
- Condon, W.S. (1979) Neonatal entrainment and enculturation. In M. Bullowa (ed) **Before Speech: The Beginnings of Interpersonal Communication**. Cambridge: Cambridge University press.
- Condon, W.S. (1980) The relationship of interactional synchrony to cognitive and emotional processes. In M.R. Key (ed) **The Relationship of Verbal and Nonverbal Communication**. The Hague: Mouton Publishers.
- Condon W.S. and Ogston, W.D. (1967) A segmentation of behaviour. **Journal of Psychiatric Research**, 5, 221-235.
- Condon, W.S. and Sander, L.W. (1974) Neonate movement is synchronised with adult speech: interactional participation and language acquisition. **Science**, 183 (4120), 99-101.
- Cooley, C. Horton (1902) Looking-Glass Self. In J.G. Manis and B.N. Meltzer (eds) (1967) **Symbolic Interaction - a reader in social psychology**. Boston: Alyn and Bacon, Inc.
- Coupe, J., Barton, L., Barber, M., Collins, L., Levy, D. and Murphy, D (1985) **Affective Communication Assessment**. Melland School, Manchester.
- Cunningham, C. (1983) Early Support and Intervention: The HARC Infant Programme. In P. Mittler and H. McConachie (eds) **Parents, Professionals and Mentally Handicapped People. Approaches to Partnership**. London: Croom Helm.
- Cunningham, C. (1985) Training and education approaches for parents of children with special needs. **British Journal of Medical Psychology**, 58, 285-305.
- Danziger, K. (1976) **Interpersonal Communication**. Oxford: Pergamon Press.
- Darwin, C. (1872) **The Expression of Emotion in Animals and Man**. London: Methuen.
- Davis, Flora. (1971) How to read body language. In Haig A. Bosmajian (ed) **The Rhetoric of Nonverbal Communication**. Glenview, Illinois: Scott, Foresman and Company.
- Deich, R.F. and Hodges, P.M. (1977) **Language without Speech**. London: Souvenir Press (Educational and Academic) Ltd.

- Deutsch, D. (ed) (1982) **The Psychology of Music**. New York: Academic Press.
- Diserens, Charles, M. (1948) In Dorothy M. Schullion and Max Schoen (eds) **Music and Medicine**. New York: Henry Schuman, Inc.
- Dowd, J. and Tronick, E. (1983) Methods for the quantitative analysis of infant limb movements. In G. Young (ed) **Manual Specialisation and the Developing Brain**. New York: Academic Press.
- Duncan, S. (1980) Describing face-to-face interaction. In Walburga von Raffler-Engel (ed) **Aspects of nonverbal communication**. Bath: Swets and Zeitlinger B.V., Lisse. (The Pitman Press).
- Duncan, S. and Fiske, D.W. (1977) **Face-to-Face Interaction: Research Methods and Theory**. Hillsdale, N.J.: Lawrence Erlbaum Associates.
- Dunst, C. J. (1980) **A clinical and educational manual for use with the Uzgis-Hunt Scales for infant development**. Baltimore: University Park Press.
- Dunst, C.J. (1982) The clinical utility of Piagetian-based scales of infant development. *Infant Mental Health Journal*, 3 (4), 259-275.
- Dunst, C.J. (1985) Communicative competence and deficits: effects of early social interactions. In E. McDonald and D. Gallagher (eds) **Facilitating Social Emotional Development in Multiply Handicapped Children**. Philadelphia: Home of the Merciful Saviour for Crippled Children.
- Eibl-Eibesfeldt, I. (1972) Similarities and differences between cultures in expressive movements. In R.A. Hinde (ed) **Nonverbal Communication**. Cambridge: Cambridge University Press.
- Ellis, N.R., Deacon, J.R., Harris, L.A., Poor, A., Angers, D., Diono, M.S., Watkins, R.S., Boyd, B.D. and Cavalier, A.R. (1982) Learning, memory and transfer in profoundly, severely, and moderately mentally retarded persons. *American Journal of Mental Deficiency*, 87(2), 186-196.
- Emde, R. N. (1984) Levels of Meaning for Infant Emotions: A Biosocial View. In K. Schere and P. Ekman (eds) **Approaches to Emotion**. Hillsdale, N.J.: Lawrence Erlbaum Associates.
- Evans, P. and Ware, J. (1987) **'Special Care' Provision. The Education of Children with Profound and Multiple Learning Difficulties**. Windsor: NFER-Nelson.

- Evarts, E.V., Wise, S.P. and Bousfield, D. (1985) **The Motor System in Neurobiology**. Amsterdam: Elsevier Biomedical Press.
- Fafouti-Milenkovic, M. and Uzgiris, I.C. (1979) The mother-infant communication system. **New Directions for Child Development**, 4, 41-56.
- Feldstein, S. (1978) A chronography of conversation: In defense of an objective approach. In A.W. Siegman and S. Feldstein (eds), **Nonverbal behavior and communication**. Hillsdale, N.J.: Erlbaum Associates.
- Fernald, A. (1985) Four-month-old infants prefer to listen to motherese. **Infant Behavior and Development**, 8, 181-195.
- Field, T.M. and Fox, N.A. (eds) (1985) **Social Perception in Infants**. Norwood, N.J.: Ablex Publishing Corporation.
- Fraiberg, S. (1968) Parallel and divergent patterns in blind and sighted infants. **Psychoanalytic Study of the Child**, 23, 264-300.
- Fraiberg, S. (1974) Blind infants and their mothers: An examination of the sign system. In M. Lewis and L.A. Rosenblum (eds) **The Effect of the Infant on its Caregiver**. New York: Wiley.
- Fraiberg, S. (1980) **Clinical Studies in Infant Mental Health. The First Year of Life**. London: Tavistock Publications.
- Fraisse, Paul. (1982) Rhythm and Tempo. In D. Deutsch (ed) **The Psychology of Music**. New York: Academic Press.
- Frank, Lawrence K. (1971) Tactile communication. In Haig A. Bosmajian (ed) **The Rhetoric of Nonverbal Communication**. Glenview, Illinois: Scott, Foresman and Company. (From **Genetic Psychology Monographs** 56, copyright 1957, by permission of the Co-executor, Estate of Lawrence. K. Frank)
- Fraser, W.I. (1991) Communication and behaviour disorders. In W.I. Fraser, R.C. MacGillivray and A.M. Green (eds) **Hallas' Caring for People with Mental Handicaps**. Oxford: Butterworth-Heinemann, Ltd. 8th edition.
- Fraser, W.I. and Green, A.M. (1991) Changing perspectives on mental handicap. In W.I. Fraser, R.C. MacGillivray and A.M. Green (eds) **Hallas' Caring for People with Mental Handicaps**. Oxford: Butterworth-Heinemann, Ltd. 8th edition.

- Freedman, D.G. (1964) Smiling in blind infants and the issue of innate versus acquired. *Journal of Child Psychology and Psychiatry*, 5, 171-184.
- Fryers, T. (1984) **The Epidemiology of Severe Intellectual Impairment: The Dynamics of Prevalence**. London: Academic Press.
- Gaddes, W.H. (1980) **Learning Disabilities and Brain Function**. New York: Springer-Verlag.
- Gearhart, B.R. (1981) **Learning Disabilities. Educational Strategies**. St. Louis; Toronto; London: The C.V. Mosby Company. 3rd edition.
- Gleason, J. (1988) Intent on Play: Social-cultural Dimensions of the Group Life of Persons with Profound Development Disabilities. *European Journal of Special Needs Education*, 3 (4), 239-251.
- Goldin-Meadow, S. and Feldman, H. (1977) The development of language-like communication without a language model. *Science*, 197, 401-403.
- Hall, Edward, T. (1959) **The Silent Language**. New York: Doubleday and Company, Inc.
- Hanson, Howard (1948) Emotional Expression in Music. In Dorothy M. Schullion and Max Schoen (eds) **Music and Medicine**. New York: Henry Schuman, Inc.
- Hargreaves, David, J. (1986) **The Developmental Psychology of Music**. Cambridge: Cambridge University Press.
- Heron, A. and Myers, M. (1983) **Intellectual Impairment. The battle against handicap**. London: Academic Press.
- Heslin, Richard and Alper, Tari (1983) Touch. A Bonding Gesture. In John M. Wiemann and Randall P. Harrison (eds) **Nonverbal Interaction**. Beverly Hills; London; New Delhi: Sage Publications.
- Hodapp, R.A. and Mueller, E. (1982) Early social development. In B. Wolman (ed) **Handbook of Developmental Psychology**. Englewood Cliffs, N.J.: Prentice-Hall.
- Hodapp, R.A., Burack, J.A. and Zigler, E. (1990) The developmental perspective in the field of mental handicap. In R.M. Hodapp, J.A. Burack and E. Zigler (eds) **Issues in the developmental approach to mental retardation**. Cambridge: Cambridge University Press.

- Hodapp, R.M., Burack, J.A. and Zigler, E. (1990) New directions in the developmental approach. In R.M. Hodapp, J.A. Burack and E. Zigler (eds) **Issues in the developmental approach to mental retardation**. Cambridge: Cambridge University Press.
- Hogg, J. (1991) Developments in Further Education for Adults with Profound Intellectual and Multiple Disabilities. In J. Watson (ed) **Innovatory Practice and Severe Learning Difficulties**. Edinburgh: Moray House Publications.
- Hogg, J. and Sebba, J. (1986) **Profound Retardation and Multiple Impairment, Vol 2: Education and Therapy**. London: Croom Helm.
- Hogg, J. and Raynes, N. (eds) (1987) **Assessment in Mental Handicap: A Guide to assessment Practices, Tests and Checklists**. London: Croom Helm.
- Houghton, J., Bronicki, G. and Guess, D. (1987) Opportunities to express preferences and make choices among students with severe disabilities in classroom settings. **Journal of Association for Persons with Severe Handicaps**, 12 (1), 18-27.
- Hubley, P. and Trevarthen, C. (1979) Sharing a task in infancy. **New Directions for Child Development**, 4, 57-80.
- Hughes, Charles W. (1948) Rhythm and Health. In Dorothy M. Schullion and Max Schoen (eds) **Music and Medicine**. New York: Henry Schuman, Inc.
- Izard, Carroll, E. (1978) On the ontogenesis of emotions and emotion-cognition relationships in infancy. In M. Lewis and L.A. Rosenblum (eds) **The Development of Affect**. New York: Plenum Press.
- Jaffe, J. and Anderson, S. (1979) Communication rhythms and the evolution of language. In A.W. Siegman and S. Feldstein (eds) **Of speech and time**. Hillsdale, N.J.: Lawrence Erlbaum Associates.
- Jaffe, J., Feldstein, S., Beebe, B., Crown, C. L., Jasnow, M., Fox, H. E., Anderson, S. W. and Gordon, S. (1990) **Interpersonal Timing and Infant Social Development**. Final Report for National Institute of Mental Health.
- Jones, L.M., Reid, B.D. and Kiernan, C.C. (1982) Signs and symbols: the 1980 survey. **Special Education: Forward Trends**, 9, 34-37.
- Jones, O.H.M. (1977) Mother-Child Communication with Pre-Linguistic Down's Syndrome and Normal Infants. In H.R. Schaffer (ed) **Studies in Mother-Infant Interaction**. London: Academic Press, Inc.

- Kahn, J.V. (1975) Utility of the Uzgiris and Hunt Scales of sensorimotor development with severely and profoundly retarded children. **American Journal of Mental Deficiency**, 80 (6) 663-665.
- Kahn, J.V. (1992) Predicting adaptive behaviour of severely and profoundly mentally retarded children with early cognitive measures. **Journal of Intellectual Disability Research**, 36, 101-114.
- Kendon, A. (1970) Movement coordination in social interaction: some examples described. **Acta Psychologica**, 32, 100-125.
- Kendon, A. (1972) Review of "Kinesics and Context": Essays on Body-Motion Communication by Ray L. Birdwhistell. **American Journal of Psychology**, 85, 441-455.
- Kendon, A. (1973) The role of visible behaviour in the organisation of social interaction. In M. von Cranach and I. Vine (eds) **Social Communication and Movement**. London: Academic Press.
- Kendon, A. (1981) Introduction. In A. Kendon (ed) **Nonverbal Communication, Interaction and Gesture**. The Hague: Mouton Publishers.
- Kendon, A. (1982) The organisation of behaviour in face-to-face interaction: observations in the development of a methodology. In K. Scherer and P. Ekman (eds) **Handbook of Methods in Non-Verbal Behaviour Research**. Cambridge: Cambridge University Press.
- Kendon, A. (1983) Gesture and speech. How they interact. In John M. Wiemann and Randall P. Harrison (eds) **Nonverbal Interaction**. Beverly Hills; London; New Delhi: Sage Publications.
- Kennell, J., De Chateau, P., and Wasz-Höckert, O. (1987) John Lind Memorial Symposium. **Infant Mental Health Journal**, 8 (3), 190-209.
- Key, M. R. (1977a) **Nonverbal Communication: A Research Guide and Bibliography**. Metuchen, N. J.: The Scarecrow Press.
- Key, M.R. (1975) **Paralanguage and Kinesics**. Metuchen, N.J.: The Scarecrow Press.
- Key, M.R. (1980) Language and Nonverbal Behavior as Organisers of Social Systems. In M.R. Key (ed) **The Relationship of Verbal and Nonverbal Communication**. The Hague: Mouton Publishers.

- Kiernan, C. C. (1977) Alternatives to speech: a review of research on manual and other forms of communication with the mentally handicapped and other non-communicating populations. **British Journal of Mental Subnormality**, 23, 8-24.
- Kiernan, C. C. (1984) The development of communication and cognition. In J. Dobbing, A.D.B. Clarke, J.A. Corbett, J. Hogg and R.O. Robinson (eds) **Scientific Studies in Mental Retardation**. London: The Royal Society of Medicine and the MacMillan Press Ltd.
- Kiernan, C. C. and Reid, B. (1986) **Pre-verbal Communication Schedule**. Windsor: NFER-Nelson.
- Kiernan, C.C., Jordan, R. and Saunders, C. (1978) **Starting Off: Establishing Play and Communication in the Handicapped Child**. London: Souvenir Press (Educational and Academic) Ltd.
- Kiernan, C.C., Reid, B.D. and Goldbart, J. (1987) **Foundations of Communication and Language**. Manchester: Manchester University Press.
- Kiernan, C.C. Reid, B.D. and Jones, L.M. (1982) **Signs and Symbols: A Review of Literature and Survey of the Use of Non-Vocal Communication Systems**. London: Heineman.
- Klaus, Marshall H. and Kennell, John H. (eds) (1982) **Parent-Infant Bonding**. St. Louis, Missouri: The C.V. Mosby Company.
- Knight, C. (1991) Developing Communication through Interaction. In J. Watson (ed) **Innovatory Practice and Severe Learning Difficulties**. Edinburgh: Moray House Publications Unit.
- Knight, C. and Watson, J. (1990) **Intensive Interactive Teaching at Gogarburn School**. Edinburgh: Moray House Publications Unit.
- Komisaruk, Barry R. (1982) Visceral-Somatic Integration in Behavior, Cognition and "Psychosomatic" Disease. In Jay S Rosenblatt, Robert A. Hinde, Colin Beer and Marie-Claire Busnel (eds) **Advances in the Study of Behavior**. New York: Academic Press.
- Kopp, C.B. and Recchia, S.L. (1990) The issues of multiple pathways in the development of handicapped children. In R.M. Hodapp, J.A. Burack and E. Zigler (eds) **Issues in the developmental approach to mental retardation**. Cambridge: Cambridge University Press.
- Koto, T., Takahashi, E., Sawada, K., Kobayashi, N., Watanabe, T. and Ishi, T. (1983) A computer analysis of infant movements synchronised with adult speech. **Paediatric Research**, 17, 625-628.

- Krout, Maurice H. (1971) Symbolism. In Haig A. Bosmajian (ed) **The Rhetoric of Nonverbal Communication**. Glenview, Illinois: Scott, Foresman and Company.
- Kugiumatzakis, J.E. (1985) **The Origin, Development and Function of Early Infant Imitation**. Unpublished Doctoral Thesis, University of Uppsala (Acta Universitatis, 35).
- Landry, S.H. and Loveland, K.A. (1988) Communication Behaviours in Autism and Developmental Language Delay. **Journal of Child Psychology and Psychiatry**, 29 (5), 621-634.
- Latchford, G. (1989) **Towards an Understanding of Profound Mental Handicap**. Unpublished Doctoral Thesis, University of Edinburgh.
- Lenneberg, Eric H. (1967) **Biological Foundations of Language**. New York: John Wiley and Sons.
- Leudar, I. (1981) Strategic communication in mental retardation. In W.I. Fraser and R. Grieve (eds) **Communicating with Normal and Retarded Children**. Bristol: John Wright and Sons Ltd.
- Lewis, M. and Brooks-Gunn, J. (1979) **Social Cognition and the Acquisition of Self**. New York: Plenum Press.
- Lewis, M. and Rosenblum, L. (eds) (1974) **The Effect of the Infant on its Caregiver**. New York: Wiley.
- Lipsitt, L. P. and Rovee-Collier, C. (eds) (1984) **Advances in Infancy Research, Vol. 3**. Norwood, N. J.: Ablex Publishing Corporation.
- Lloyd, L.L. and Karlan, G.R. (1984) Non-Speech Communication Symbols and Systems: Where have we been and where are we going? **Journal of Mental Deficiency Research**, 28, 3-20.
- Mackay, G. (1989) The School Years. In W.I. Fraser, R.C. MacGillivray and A.M. Green (eds) **Hallas' Caring for People with Mental Handicaps**. Oxford: Butterworth-Heinemann, Ltd. 8th edition.
- MacPherson, F. and Butterworth, G. (1988) Sensorimotor intelligence in severely mentally handicapped children. **Journal of Mental Deficiency Research**, 32, 465-478.
- Marfo, K. (1984) Interactions between mothers and their mentally retarded children: Integration of research findings. **Journal of Applied Psychology**, 5, 45-69.

- Mayo, C. and Henley, N.M. (1981) Nonverbal behaviours: barrier or agent for sex role change. In C. Mayo and N.M. Henley (eds) **Gender and Nonverbal Behavior**. New York: Springer-Verlag.
- McLean, J. and Snyder-McLean, L. (1987) Form and function of communicative behaviour among persons with severe developmental disabilities. **Australian and New Zealand Journal of Development Disability**, 13, 83-98.
- Meerlo, Joost. (1971) Rhythm in babies and adults. In Haig A. Bosmajian (ed) **The Rhetoric of Nonverbal Communication**. Glenview, Illinois: Scott, Foresman and Company.
- Meltzoff, A.N. and Moore, M.K. (1977) Imitation of facial and manual gestures by human neonates. **Science**, 198 (4312), 75-78.
- Meltzoff, A.N. and Moore, M.K. (1983) Newborns imitate adult facial gestures. **Child development**, 54, 702-709.
- Meltzoff, A.N. and Moore, M.K. (1985) Cognitive foundations and social functions of imitation and intermodal representation in infancy. In Jaques Mehler and Robin Fox (eds) **Neonate Cognition: Beyond the Blooming Buzzing Confusion**. Hillsdale, N. J.: Lawrence Erlbaum Associates.
- Meltzoff, A.N. and Moore, M.K. (1992a) Early Imitation Within a Functional Framework: The Importance of Person Identity, Movement and Development. **Infant Behavior and Development**, 15 (4), 479-505.
- Meltzoff, A.N. (1992b) Imitation as a social-communicative encounter. In Tiffany M. Field (Special Editor) **Infant Behavior and Development**, 15, Abstracts Issue, Eighth International Conference on Infants Studies, Florida. Norwood, N. J.: Ablex Publishing Corporation.
- Mirenda, P. and Iacono, T. (1988) Strategies for promoting augmentative and alternative communication in natural contexts with students with autism. **Focus on Autistic Behavior**, 4 (4), 1-16.
- Mittler, P.J. (1970) Cognitive Processes: Piaget's Approach. In P.J. Mittler (ed) **The Psychological Assessment of Mental and Physical Handicaps**. London: Methuen and Co. Ltd.
- Mittler, P.J. (1979) Patterns of partnership between parents and professionals. **Teaching and Training**, 17, 111-116.

- Mittler, P. J. (1992) **Assessing People with Mental Retardation: An Overview.** In **Assessment of People with Mental Retardation.** Publication by Division of Mental Health, World Health Organisation, Geneva.
- Moore, Bert and Underwood, Bill (1981) The development of prosocial behavior. In Sharon S. Brehm, Saul M. Kassin and Frederick X. Gibbons (eds) **Developmental Social Psychology.** Oxford: Oxford University Press.
- Moore-Ede, Martin C., Sulzman, Frank M. and Fuller, Charles, A. (1982) **The Clocks That Time Us.** Physiology of the Circadian Timing System. Cambridge, Mass.: Harvard University Press.
- Morgan, G.A. and Ricciuti, H.N. (1965) Infants' Responses to Strangers During the First Year. In B.M. Foss (ed) **Determinants of Infant Behaviour.** London: Methuen and Co. Ltd.
- Morris, D. (1979) **Intimate Behaviour.** St. Albans, Herts.: Triad/Panther Books.
- Murphy, G. (1987) Direct Observation as an Assessment Tool in Functional Analysis and Treatment. In J. Hogg and N. Raynes (eds) **Assessment in Mental Handicap: A Guide to assessment Practices, Tests and Checklists.** London: Croom Helm.
- Murray, L. (1980) **The Sensitivities and Expressive Capacities of Young Infants in Communication with Others.** Unpublished Doctoral Thesis, University of Edinburgh.
- Murray, L. and Trevarthen, C. (1985) Emotional regulation of interactions between two-month-olds and their mothers. In T. Field and N. Fox (eds) **Social Perception in Infants.** Norwood, N.J.: Ablex Publishing Company.
- Murray, L. and Trevarthen, C. (1986) The infant's role in mother-infant communication. **Journal of Child Language**, 13, 15-29.
- National Development Team for Mentally Handicapped People (1985) **4th Report, 1981 - 84.** London: HMSO.
- Negayama, K. (1991) Personal communication. Department of Psychology, Mukogawa Women's University, Hyogo, Japan.
- Newson, E. (1981) Parents as a Resource in Diagnosis and Assessment. In A. Brechin, P. Liddiard and J. Swain (eds) **Handicap in a Social World.** Suffolk: Hodder and Stoughton (in association with the Open University Press).

- Newson, J. (1977) An Intersubjective Approach to the Systematic Description of Mother-Infant Interaction. In H.R. Schaffer (ed) **Studies in Mother-Infant Interaction**. London: Academic Press, Inc.
- Newson, J. (1979) The growth of shared understandings between infant and caregiver. In M. Bullowa (ed) **Before Speech: The Beginnings of Interpersonal Communication**. Cambridge: Cambridge University Press.
- Newson, J. and Newson, E. (1975) Intersubjectivity and the Transmission of Culture. **Bulletin of the British Psychological Society**, 28, 437-46.
- Nind, M. and Hewett, D. (1988) Interaction as Curriculum. **British Journal of Special Education**, 15 (2), 55 - 57.
- O'Toole, R. and Dubin, R. (1968) Baby feeding and body sway: An experiment in George Herbert Mead's "taking the role of the other." **Journal of Personality and Social Psychology**, 10, 59-65.
- Ogan, T. and Wladen, T. (1992) States of engagement and infant social referencing. In Tiffany M. Field (Special Editor) **Infant Behavior and Development**, 15, Abstracts Issue, Eighth International Conference on Infants Studies, Florida. Norwood, N. J.: Ablex Publishing Corporation.
- Oster, H. (1978) Facial Expressions and Affect Development. In M Lewis and L.A. Rosenblum (eds) **The Development of Affect**. New York: Plenum Press.
- Ouvry, C. (1987) **Educating Children with Profound Handicaps**. Birmingham: BIMH Publications.
- Papousek H. and Papousek, M. (1988) Ontogeny of Social Interactions in Newborn Infants. In C. von Euler, H. Forssberg and H. Lagercrantz (eds) **Neurobiology of Early Infant behaviour**. Stockholm: Stockton Press.
- Parker-Price, S., Cooper, R.P., Culp, A.M. and Culp, R.E. (1992) Comparisons of Prosodic Features in Infant-Directed Speech between Teenage and Adult Mothers. In Tiffany M. Field (Special Editor) **Infant Behavior and Development**, 15, Abstracts Issue, Eighth International Conference on Infants Studies, Florida. Norwood, N. J.: Ablex Publishing Corporation.
- Parkes, C.M. and Stevenson-Hinde, J. (eds) (1982) **The Place of Attachment in Human Behaviour**. London: Tavistock Publications Ltd.

- Pawlby, S.J. (1977) Imitative Interaction. In H.R. Schaffer (ed) **Studies in Mother-Infant Interaction**. London: Academic Press, Inc.
- Peery, J.C. (1980) Neonate-adult head movement: No and yes revisited. **Developmental Psychology**, 16, 245-250.
- Pegg, J.E., Werker, J.F. and McLeod, P.J. (1992) Infants under 4-months prefer Cantonese infant-directed speech: Study 11. In Tiffany M. Field (Special Editor) **Infant Behavior and Development**, 15, Abstracts Issue, Eighth International Conference on Infants Studies, Florida. Norwood, N. J.: Ablex Publishing Corporation.
- Piaget, J. (1951) **Play, Dreams and Imitation in Childhood**. London: Methuen and Co. Ltd.
- Piaget, J. (1954) **The Construction of Reality in the Child**. New York: Basic Books.
- Piaget, J. and Inhelder, B. (1969) **The psychology of the child**. London: Routledge and Kegan Paul.
- Ploog, D. (1979) Phonction, emotion, cognition, with reference to the brain mechanisms involved. In **Brain and Mind: CIBA Foundation Symposium 69**. Amsterdam: Excerpta Medica.
- Plutchik, R. (1968) **Foundations of Experimental Research**. New York: Harper and Row Publishers. 2nd edition.
- Presland, J.L. (1982) **Paths to Mobility in Special Care**. Kidderminster: British Institute for Mental Handicap.
- Priesler, G. and Palmer, C. (1986) The function of vocalisation in early parent-blind child interaction. In B. Lindblom and R. Zetterstrom (eds) **Precursors of Early Speech**. Basingstoke: The Macmillan Press Ltd.
- Reid, B.D., Jones, L.M. and Kiernan, C.C. (1983) Signs and symbols - the 1982 survey of use. **Special Education-Forward Trends**, 10, 27-28.
- Repp, A.C., Barton, L.E. and Brulle, A.R. (1981) Correspondence between effectiveness and staff use of instructions for severely retarded persons. **Applied research in Mental Retardation**, 2 (3), 237-245.
- Resch, R.C. (1981) Natural Observation Studies: Methodology and Video recordings in Spontaneous Behavior Settings. **Infant Mental Health Journal**, 2 (3), 176-187.

- Richards, M.P.M. (1974) First steps in becoming social. In M.P.M. Richards (ed) **The integration of the child into the social world**. Cambridge: Cambridge University Press.
- Richards, S. and Sternberg, L. (1992) A preliminary analysis of environmental variables affecting the observed biobehavioural states of individuals with profound handicaps. **Journal of Intellectual Disability Research**, 36, 403-414.
- Robertson, D.L.D. (1990) **The Behaviour of 'Profoundly Mentally Handicapped' Children in Interactions with Familiar and Unfamiliar Caregivers, and the Caregivers' Use of 'Action Cycles'**. Unpublished Psychology Hons. Thesis, Dept. of Psychology, University of Edinburgh.
- Robson, C. (1973) **Experiment, Design and Statistics in Psychology**. Harmondsworth: Penguin Books Ltd.
- Rogoff, B. (1990) **Apprenticeship in Thinking: Cognitive development in Social Context**. New York: Oxford University Press.
- Rogers, S.J. (1977) Characteristics of the Cognitive Development of Profoundly Retarded Children. **Child Development**, 48 (3), 837-843.
- Rondal, J.A. (1984) Linguistic Development in Mental Retardation. In J. Dobbing, A.D.B. Clarke, J.A. Corbett, J. Hogg and R.O. Robinson (eds) **Scientific Studies in Mental Retardation**. London: The Royal Society of Medicine and the MacMillan Press Ltd.
- Rosenfeld, M.M. (1978) Conversational control functions of nonverbal behaviour. In A.W. Siegman and S. Feldstein (eds) **Nonverbal Behaviour and Communication**. Hillsdale, N.J.: Lawrence Erlbaum Associates.
- Ross, H. S. and Goldman, B. D. (1977) Establishing New Social Relations in Infancy. In Thomas Alloway, Patricia Pliner and Lester Krames (eds) **Attachment Behavior. Advances in the Study of Communication and Affect, Vol. 3**. New York: Plenum Press.
- Sachs, Curt (1953) **Rhythm and Tempo**. London: J.M. Dent and Sons Ltd.
- Salk, L. (1962) Mothers' heartbeat as imprinting stimulus. **Trans. New York Acad. Sci.**, 24, 753-763.
- Schaffer, H.R. (1971) **The Growth of Sociability**. Harmondsworth: Penguin Books Ltd.

- Schaffer, H.R. (1977) Early Interactive Development. In J. Oates (ed) **Early Cognitive Development**. London: The Open University press.
- Schaffer, H.R, Collis, G.M. and Parsons, G. (1977) Vocal Interchange and Visual Regard. In H.R. (ed) **Studies in Mother-Infant Interaction**. London: Academic Press, Inc.
- Schefflen, A.E. (1964) The significance of posture in communication systems. **Psychiatry**, 27, 316-331.
- Schlesinger, Hilde S. (1987) Effects of Powerlessness on Dialogue and Development: Disability, Poverty, and the Human Condition. In Bruce W. Heller, Louis M. Flohr and Leonard S. Zegans (eds) **Psychosocial Intervention with Sensorially Disabled Persons**. San Diego; London; San Fransisco: Grune & Stratton Inc.
- Schlosser, R. and Lloyd, L. (1991) Augmentative and alternative communication: An evolving field. **Augmentative and Alternative Communication**, 7 (3), 154-160.
- Schwartz, C.B. and Michel, G.F. (1992) Posture and Head Orientation Affects Patterns of Manual Coordination in 11-25 Hour Old Human Neonates. In Tiffany M. Field (Special Editor) **Infant Behavior and Development**, 15, Abstracts Issue, Eighth International Conference on Infants Studies, Florida. Norwood, N.J.: Ablex Publishing Corporation.
- Shanley, E. (1986) Social causes of mental handicap. In E. Shanley (ed) **Mental Handicap - A Handbook of Care**. Edinburgh: Churchill Livingstone.
- Smith, E. , Goodman, K. and Meredith, R. (1976) **Language and Thinking in School**. New York: Holt, Rheinhart and Winston, Inc. 2nd edition.
- Sollberger, A. (1965) **Biological Rhythm Research** Amsterdam: Elsevier Publishing Co.
- Stansfield, J. (1989) Augmentative and alternative systems of communication. In W.I. Fraser, R.C. MacGillivray and A.M. Green (eds) **Hallas' Caring for People with Mental Handicaps**. Oxford: Butterworth-Heinemann, Ltd. 8th edition.
- Stern, D. (1977) **The First Relationship: Infant and Mother**. Glasgow: Fontana/Open Books.
- Stern, D. (1985) **The Interpersonal World of the Infant**. New York: Basic Books.

- Stern, D. and Gibbon, J. (1980) Temporal expectancies of social behaviours in mother-infant play. In E. Thoman (ed) **Origins of Infant Social Responsiveness**. New York: Basic Books.
- Stern, D., Jaffe, J., Beebe, B. and Bennett, S.L. (1975) Vocalising in unison and in alternation: two modes of communication within the mother-infant dyad. *Annals of New York Academy of Sciences*, 263, 89-100.
- Sternberg, L. and Owens, A. (1985) Establishing pre-language signalling behaviour with profoundly mentally handicapped students: a preliminary investigation. *Journal of Mental Deficiency Research*, 25, 81-93.
- Stow, L. and Selfe, L. (1989) **Understanding children with special needs**. London: Unwin Hyman Ltd.
- Trad, P.V. (1990) **Infant Previewing: Predicting and Sharing Interpersonal Outcome**. New York: Springer-Verlag.
- Trevarthen, C. (1977) Descriptive analyses of infant communication behaviour. In H.R. (ed) **Studies in Mother-Infant Interaction**. London: Academic Press, Inc.
- Trevarthen, C. (1979) Communication and co-operation in early infancy: a description of primary intersubjectivity. In M. Bullowa (ed) **Before Speech: The Beginnings of Interpersonal Communication**. Cambridge: Cambridge University Press.
- Trevarthen, C. (1983) Interpersonal abilities of infants as generators for transmission of language and culture. In A. Oliverio and M. Zapella (eds) **The Behavior of Human Infants**. London: Plenum Press.
- Trevarthen, C. (1984) How control of movement develops. In H.T.A. Whiting (ed) **Human Motor Action - Bernstein Reassessed**. Amsterdam: Elsevier Science Publishers.
- Trevarthen, C. (1985) Facial expressions of emotion in mother-infant interaction. *Human Neurobiology*, 4, 21-32.
- Trevarthen, C. (1986a) Development of intersubjective motor control in infants. In M.G. Wade and H.T.A. Whiting (eds) **Motor Development in Children: Aspects of Coordination and Control**. Dordrecht: Martinus Nijhof.
- Trevarthen, C. (1986b) Form, significance and psychological potential of hand gestures in infants. In J.L. Nespoulous, P. Perron and A. Roch Lecours (eds) **The Biological Foundation of Gestures: Motor and Semiotic aspects**. Cambridge, Mass.: MIT Press.

- Trevarthen, C. (1988) Development of early social interactions and the affective regulation of brain growth. In C. von Euler, H. Forssberg and H. Lagercrantz (eds) **Neurobiology of Early Infant Behaviour**. Basingstoke, Hants: Stockton Press.
- Trevarthen, C. (1990) Consciousness in Infancy: Its Origins, Motives and Causal Potency. Presentation to Conference - **"Molecules and the Mind": The Mind/Body Problem in Epistemology and the History of Science**, Isola di San Giorgio Maggiore, Venice.
- Trevarthen, C. (1992) The self born in intersubjectivity: The psychology of an infant communicating. In U. Neisser (ed) **Ecological and Interpersonal Knowledge of the Self**. New York: Cambridge University Press.
- Trevarthen, C. and Hubley, P. (1978) Secondary intersubjectivity: Confidence confiding and acts of meaning in the first year. In A Lock (ed) **Action, Gesture and Symbol: the emergence of language**. London: Academic Press.
- Trevarthen, C. and Sylvester-Bradley, B. (1978) Baby-talk as an adaptation to the infant's communication. In N. Waterson and C. Snow (eds) **Development of Communication: Social and Pragmatic Factors in Language Acquisition**. London: Wiley and Sons.
- Trevarthen, C. and Marwick, H. (1986) Signs of motivation for speech in infants, and the nature of a mother's support for development of language. In B. Lindblom and R. Zetterstrom (eds) **Precursors of Early Speech**. Basingstoke: The Macmillan Press Ltd
- Trevarthen, C., Murray, L. and Hubley, P. (1981) Psychology of infants. In J. Davis and J. Dobbing (eds) **Scientific Foundations of Clinical Pediatrics**. London: W. Heinemann Medical Books Ltd. 2nd edition.
- Tronick, E. and Adamson, L. (1980) **Babies as people: New findings on our social beginnings**. New York: Collier Books.
- Trowell, J. (1982) Effects of obstetric management on the mother-child relationship. In C.M. Parkes and J. Stevenson-Hinde (eds) **The Place of Attachment in Human Behaviour**. London: Tavistock Publications Ltd.
- Urwin, C. (1978) The development of communication between blind infants and their parents. In A Lock (ed) **Action, Gesture and Symbol: the emergence of language**. London: Academic Press.
- Uzgiris, I. and Hunt, J. (1975) **Assessment in infancy: Ordinal Scales of psychological development**. Urbana, Il.: University of Illinois Press.

- van Dijk, J. (1965) **The first steps of the deaf/blind child towards language.** Proceedings of the Conference on the Deaf/Blind, Refnes, Denmark. Boston; Perkins School for the Blind.
- van Rees, S. (1992) **Video production: Video Interaction Support in Hospital.** Stichting Lichaamstal, Heijthuisen, The Netherlands.
- Volkmar, F.R., Burack, J. and Cohen, D. (1990) Deviance and developmental approaches in the study of autism. In R.M. Hodapp, J.A. Burack and E. Zigler (eds) **Issues in the developmental approach to mental retardation.** Cambridge: Cambridge University Press.
- von Cranach, M. and Vine, I. (1973) **Social Communication and Movement.** London: Academic Press.
- Walker, M. (1978) The Makaton Vocabulary. In T. Tebbs (ed) **Ways and Means.** Basingstoke: Globe Educational.
- Ware, J. and Evans, P. (1986) Interactions between profoundly handicapped pupils and staff in a special care class. In J.M. Berg (ed) **Science and Service in Mental retardation: Proceedings of the Seventh Congress of the International Association for the Scientific Study of Mental Deficiency.** London: Methuen and Co. Ltd.
- Ware, J. and Evans, P. (1987) Room Management is not Enough. **British Journal of Special Needs Education**, 14 (2), 78-80.
- Waters, E. (1978) The reliability and stability of individual differences in infant-mother attachment. **Child Development**, 49, 483-494.
- Watts, F. (1987) Editorial remarks. In J. Clements **Severe Learning Disability and Psychological Handicap.** Chichester: John Wiley and Sons.
- Watzlawick, P., Beavin, J. and Jackson, D.D. (1967) **Pragmatics of human communication: A study of interactional patterns, pathologies, and paradoxes.** New York: Norton.
- Wiemann, John M. and Harrison, Randall P. (eds) (1983) **Nonverbal Interaction.** Beverly Hills; London; New Delhi: Sage Publications.
- Wilson, A.R.S. (1983) The use of Manual Communication with Deaf-Blind Mentally Handicapped Children. In J. Hogg and P.J. Mittler (eds) **Advances in Mental Handicap Research, Vol. 2. Aspects of Competence in Mentally Handicapped People.** Chichester: John Wiley and Sons.

Wing, L. and Gould, J. (1979) Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. **Journal of Autism and Developmental Disorders**, 9, 11-30.

World Health Organisation (1980) **International Classification of Impediments, Handicaps and Disabilities**. Geneva: WHO.

Wright, E.C., Abbas, K.A. and Meredith, C. (1974) A study of the interactions between nursing staff and profoundly mentally handicapped children. **British Journal of Mental Subnormality**, 20, 14-17.

Yoder, P. (1986) Clarifying the Relation between Degree of Infant Handicap and Maternal Responsivity to Infant Communicative Cues: Measurement Issues. **Infant Mental Health Journal**, 7 (4), 281-293.

Appendix 1

INTERACTIVE BEHAVIOURS CODING SCHEDULE

ADULT

Hand/Body contact

This describes passive physical contact used as a communication strategy.

The adult initiates body contact as part of an active exchange in which adult and child rest against each other. Body contact used to physically support the child is excluded.

The adult intentionally rests her/his hand on the child's hand or body as part of an active exchange. Hand contact used to physically support the child or for grooming, e.g. adjusts child's clothing, is excluded.

Specific actions

The adult strokes, jiggles, shakes, rubs, tickles, rocks or bounces the child in play.

Monitor

The adult moves her/his head or body in synchrony with the child's body and head movements to maintain the best orientation for communicating with the child.

Moulding

The adult moulds her/his body position round the child's body shape.

Smile

Clear smiles which are readily observable.

Facial expressions

These are clear changes of expression. Most expressions are consciously exaggerated in fun or as part of a game - adults normally held a pleasant neutral expression when attending to the child.

Look

This includes looking in the direction of the child's face as well as direct eye contact.

Facial closeness

The adult holds her/his face closer than the normal distance for face-to-face interaction. In most cases the adult's and child's faces were only several inches apart. Games where the adult zooms in close to the child's face are recorded under 'body games'. Facial closeness implies the holding of a position.

Body games

The adult improvises a game which involves some form of body contact with the child or manipulation of the child's limbs, without the use of toys. Routine games such as 'round-and-round the garden' are also recorded under this heading, although these are less common.

Games with toys

The adult improvises a game which is focused on a toy or object, including play which incorporates body contact. (Adults rarely played with toys in a conventional way).

Sing

This includes nursery rhymes and improvised 'songs', e.g. the adult jiggles the child and 'sings' in time with the jiggling. Songs which include action games are considered to contain two co-occurring events - 'body games' and 'sings'.

Vocal

All dialogue directed at the child, including vocal interjections, e.g. "Mmmm?"

CHILD

Hand/Body Contact

This describes passive physical contact initiated by the child.

The child initiates body contact in which the child and adult rest against each other. Body contact which results inadvertently during activity initiated by the adult is excluded, e.g. a child flops against the adult when being moved from lying to sitting.

The child intentionally rest his/her hand against the adult's hand or body. Any hand contact which results from the adult's actions is excluded, e.g. the child's hand slips on to the adult's knee while he/she is being bounced on the adult's lap.

Gestural Action

The child uses a specific body movement with a specific meaning, e.g. raises a foot for a repeat of a particular body game, leans his head to one side in anticipation of having his face stroked, holds her hand in a certain way to indicate she wants her hand patted. The movement can be in any form, but must be used consistently by the child in the same context for the same purpose.

Orient

The child turns or leans his/her head or part of his/her body towards the adult. The restricted movement of many children does not exclude them from this item, e.g. a child lying on a play mat who has very restricted movement may still be able to turn part of his body in the direction of the adult.

Moulding

The child intentionally moulds his/her body position within the shape made by the adult. This usually involves some form of cuddling into the adult. Any moulding which results from the adult's actions is excluded, e.g. the adult adjusts the child's position while he is sitting in her lap and he flops into a moulded shape through poor body control.

Body Movements

Any actions involving the child's limbs, head or whole body.

Body Stirring

Minimal movement in which there is a slight arching of the body or head, or a slight shift in position, e.g. the child arches her head up and back very slightly in response to the adult's speaking to her or raises her body slightly as she vocalises. Tiny finger and head movements which are clearly observable, but involve very little change of direction or position during the movement, are also included

Smile

Clear smiles which are readily observable

Facial Movements/Expressions

Facial movements: The child widens and narrows his/her mouth and moves his/her facial muscles. These movements are not present all the time, occurring only when the adult talks/plays with the child.

Automatic mouthing movements and facial grimaces are excluded.

Facial expressions: These are clear, unambiguous changes in expression, unobscured by facial grimaces of organic origin.

Look

This includes looking in the direction of the adult's face as well as direct eye contact. Blind children who appeared to look directly at the adult in response to her/his overtures are recorded under the 'orient' category.

Vocalise

Any babbling or sound made by the child.

Appendix 2

SHARED INVOLVEMENT CODING SCHEDULE

Categories

There are four main categories, based on the PMH subject's responses:-

Solitary Activity (5 codes)

This category reflects different types of intervention by the adult in which the young person gives no response or signs of awareness that there is anyone else in the room. For example, the adult might move a young person from one position to another, offer a toy, or call his/her name, during which there is no change in what the young person is doing.

Focus on Toys (5 codes)

In this category the adult's attention is focused principally on a toy and, if he or she responds, the young person's attention is also focused more on the toy than the adult.

Physical Contact (29 codes)

This category refers to physical contact in which the young person is free to move away or disengage if he or she wishes, thus confirming that any involvement through physical contact is a voluntary act and something the young person wants to do.

Person-to-Person (6 codes)

In the Person-to-Person category the attention of the adult and young person is focused mainly on the other person and their non-object actions and nonverbal communication. Occasionally toys might be included, but they are not the focus of attention for either participant.

Levels of Involvement

Within each of the four categories it was possible to establish a sub-coding of events which, to a degree, reflected the level of involvement of the PMH subjects. Events labelled *a-k* refer to those initiated by the adult subject and those labelled *n-w* refer to events initiated by the PMH subject. Events labelled *i-iv* refer to events in which the PMH subject showed a high level of non-involvement. In sessions filmed near the end of the recording period several subjects exhibited behaviours in the Physical Contact category which were not present in the earlier

recordings used to form the basis for the schedule. These events were added to the schedule with different coding to avoid disrupting the sequence of coding already completed.

Rules for Starting, Ending and Initiating Events

PMH Subject

Determining the start of an event

The beginning of a PMH subject's response to an adult's attempts to involve him/her in some way is considered to start from the beginning of the action the PMH subject uses to respond, e.g. beginning of a smile, beginning of arm movement to reach out.

Determining the end of an event

When a PMH subject terminates an event it is considered to end at the beginning of the action he/she uses to terminate.

Scoring initiation

The PMH subject is considered to have initiated if he/she offers a toy, or reacts to, or shows awareness of the adult in some way in the absence of any prompting from the adult.

During a period of involvement with the adult, the PMH subject is considered to have initiated if this occurs after a break in the activity or interaction, however short the break, or if the PMH subject intentionally changes the activity or interaction.

Determining the start of an initiation

When a PMH subject initiates an event it is considered to start at the beginning of the action he/she uses to initiate. In the case of toys, the event begins at the beginning of the action the PMH subject uses to offer the toy and finishes when his/her hand moves off the toy.

Adult Subject

Determining the start of an initiation

When an adult subject initiates an event it is considered to begin at the start of the PMH subject's response.

Determining the end of an event

On the occasions when an adult subject terminates an event, the beginning of the action he/she uses to terminate marks the end of the event. If the PMH subject continues to participate and the adult does not respond this is recorded as a Missed Cue (MC) or Missed Toy Offer (MTO).

Co-Occurring Events

Where events co-occur, the event judged to be at the highest level of involvement is recorded as the main event and the event(s) at the lower level(s) of involvement is recorded as a secondary event. For example, if a PMH subject turns to look at an adult (Person-to-Person category) while resting his hand on her arm (Physical Contact category), then 'turning to look' is coded as the main event and 'resting a hand on arm' is the secondary event.

Sometimes a main event is superseded by a new event which implies a higher level of involvement, but the original event still continues. For example, a PMH subject and adult might be sitting together with the adult holding the young person's hand. In the absence of other events, this is classified as the main event. Then, while continuing to hold hands, the PMH subject reaches out with his free hand and pats the adult's face. The face patting becomes the main event and the continued hand holding becomes a secondary event. The latter has superseded the former because it was initiated by the PMH subject and involves active behaviours as opposed to passive sitting.

Indistinct boundaries between events

Some events can lead directly into another event with a minimal pause in between, the actual point of transition being indistinct. The beginnings and endings of these events are recorded at the midpoint between the ending of one event and the beginning of the next. An example might be where a PMH subject moves his hand away from resting on the adult's hand and, without pause, moves his hand up to pat the adult's shoulder, or a brief moment where the PMH subject waits to see what the adult will do next.

CATEGORIES

Solitary Activity

1i. Self-Absorbed Activity

The PMH subject is absorbed in his/her activity or movements, or lies, sits, stands or wanders about doing nothing, with no observable reaction to any intervention from the adult.

1ii. Passive Acceptance

The PMH subject either passively accepts a toy placed on him/her by the adult, or briefly glances at an offered toy, but does not examine or manipulate it, directing his or her attention elsewhere, or incorporates the toy into his/her on-going stereotyped behaviour, showing no observable reaction to the adult. A brief glance in the direction of the adult is also classified under this event. A glance lasts 1 second or less.

1iii. Allows Postural Adjustment

The PMH subject allows him/herself to be manoeuvred into a change of position, have his or her posture adjusted or to be moved from one spot to another, but shows no observable reaction to the adult.

1iv. Rejects

The adult's attempts at involvement are responded to, but negatively, e.g. by pushing her/him away, pulling away, moving away from one resting place to another further away, turning his/her back or throwing/pushing away an offered toy. There are no smiles or laughs and the PMH subject does not return to the adult as might be observed if such actions were part of a game. The event lasts for the duration of the action(s) used to reject.

1v. Watching

The PMH subject watches what the adult is doing, but does not become involved in the adult's actions. This event implies distance between subjects - the PMH subject watches what the adult is doing but stays too far away to be involved and does not become involved non-verbally.

Focus on Toys

In this category the actions of the adult subject are mainly directed to interesting the PMH subject in a toy, and the PMH subject's attention, when engaged, is focussed mainly the toy.

2a. *Accepts Toy*

The PMH subject looks at, examines or manipulates a toy introduced by the adult, but shows no observable reaction to the adult. The event finishes when the PMH subject stops examining or manipulating the toy, or when the adult introduces a new toy to which the PMH subject now gives his/her attention, or removes the toy and loses the PMH subject's attention. The toy may be some distance from the PMH subject when he/she looks at it.

2b. *Toy Interpersonal*

The PMH subject looks at, examines or manipulates a toy introduced by the adult and observably reacts to or shows awareness of the adult once during the period of play.

2c. *Mutual Involvement - Toy*

The PMH subject looks at, examines or manipulates a toy introduced by the adult and observably reacts to the adult or shows awareness of her/his presence or actions more than once during the period of play.

2n. *Offers Toy*

The PMH subject offers or takes a toy to the adult or leads the adult to a toy, but does not continue his/her involvement once the adult has responded. The event begins from the start of the first action the PMH subject uses to give the adult the toy.

If the adult fails to respond to the offered toy this is coded under secondary events as MTO (missed toy offer). MTO lasts for the duration of the action(s) the PMH subject uses to offer the toy.

2o. *Offers Toy Involved*

The PMH subject offers or takes a toy to the adult, or takes the adult to a toy, and continues his/her involvement once the adult has responded. The event begins from the start of the first action the PMH subject uses to give the adult a toy.

Physical Contact

This category refers to physical contact where the recipient is free to move away from the other person if he/she wishes.

Rest

Denotes inactivity. The person who is resting maintains physical contact by not moving away from the other, but does not jiggle, pat, stroke, manipulate or play with him/her.

Active

Denotes activity in which one person touches the other in the form of jiggling, patting, stroking, manipulating or playing with the other person.

Hand-to-Body Contact

One person places a hand(s) on the other person's body (excluding hands). The recipient keeps the initiator's hand(s) in contact with him/her.

Hand-to-Hand Contact

One person places a hand(s) on the other person's hand(s). The recipient keeps his/her hand(s) in contact with the initiator(s) hands.

Body Contact

One person has part or all of his/her body in contact with part or all of the other's body. The recipient keeps his/her body in contact with the initiator.

Rating as Main and Secondary Events

If no other form of participation is observable in which the PMH subject is reacting and responding to the adult the Physical Contact events are recorded as main events. If the PMH subject shows involvement through events in the Interpersonal category or the interpersonal events in the Focus on Toys category, then Physical Contact events are recorded as secondary events.

3a. Hand-to-Body Contact (Adult Init) - Mutual Rest (HBMR)

The PMH subject accepts and maintains hand-to-body contact.

3b. Hand-to-Hand Contact (Adult Init) - Mutual Rest (HHMR)

The PMH subject accepts and maintains hand-to-hand contact.

3c. Body Contact (Adult Init) - Mutual Rest (BCMR)

The adult initiates body contact with the PMH subject, who rests against the adult and is unrestrained and free to move away if he/she wishes.

3d. *Hand-to-Body Contact (Adult Init) - Adult Active (HBAA)*

The PMH subject allows hand-to body contact while the adult jiggles, pats, plays with him/her.

3e. *Hand-to-Hand Contact (Adult Init) - Adult Active (HHAA)*

The PMH subject's hand rests in contact with the adult's hand while the adult pats, jiggles, strokes or plays with his/her hand or tries to get a response in some way. There is no observable reaction to this in the PMH subject's behaviour.

3f. *Body Contact (Adult Init) - Adult Active (BCAA)*

The adult jiggles, claps, pats, rocks the PMH subject or tries to get a response in some way. The PMH subject remains rested against the adult, but there is no other observable event in his/her behaviour. The subjects can be lying, sitting or standing. If the PMH subject continues resting against the adult when the adult stops, the event becomes Body Contact (Adult Init) - Mutual Rest.

3g. *Hand-to-Body Contact (Adult Init) - PMH Active (HBSA)*

The adult's hand rests in contact with the PMH subject's body while the PMH subject is active e.g. patting adult.

3h. *Hand-to-Hand Contact (Adult Init) - PMH Active (HHSA)*

The adult's hand rests in contact with the PMH subject's hand while the PMH subject pats, strokes or plays with his/her hand. The adult remains inactive.

3i. *Hand-to-Body Contact (Adult Init) - Both Active (HBBA)*

Both the adult and PMH subject have a hand on the other's body and are active.

3j. *Hand-to-Hand Contact (Adult Init) - Both Active (HG)*

Hand Games. The adult and PMH subject pat, stroke, manipulate and play with each other's hands. The activity has a lot of repetition and is not varied like a game or interactive exchange.

3k. *Body Contact (Adult Init) - Both Active (BCBA)*

The adult and PMH subject touch, stroke, cuddle, pat each other, with part of their bodies remaining in contact.

3n. *Hand-to-Body Contact (PMH Init) - Mutual Rest (IHBMR)*

The PMH subject initiates hand-to-body contact with his/her hand remaining at rest on the adult.

3o. *Hand-to-Hand Contact (PMH Init) - Mutual Rest (IHHMR)*

The PMH subject initiates and maintains hand-to-hand contact.

3p. *Body Contact (PMH Init) - Mutual Rest (IBCMR)*

The PMH subject initiates and maintains body contact with the adult.

3q. *Hand-to-Body (PMH Init) - Adult Active (IHBA)*

The PMH subject places a hand on the adult's body then remains at rest while the adult is active.

3r. *Hand-to-Hand Contact (PMH Init) - Adult Active (IHHA)*

The PMH subject initiates hand-to-hand contact then ceases activity but remains in contact while the adult pats, plays with his/her hand.

3s. *Body Contact (PMH Init) - Adult Active (IBCA)*

The PMH subject initiates body contact then ceases further activity but remains in body contact with the adult who jiggles, pats, plays with him/her.

3t. *Hand-to-Hand Contact (PMH Init) - PMH Active (IHHS)*

The PMH subject initiates hand-to-hand contact and continues to pat, play with, manipulate the adult's hand(s) while the adult remains inactive.

3u. *Hand-to-Body Contact (PMH Init) - Both Active (IHBS)*

The PMH subject places a hand on the adult's body and continues to be active, with the adult joining in.

3v. *Hand-to-Hand Contact (PMH Init) - Both Active (IHG)*

Hand games. Both the PMH subject and the adult participate in hand-to-hand contact initiated by the PMH subject.

3w. *Body Contact (PMH Init) - Both Active (IBCBA)*

The PMH subject and adult touch, stroke, cuddle and pat each other, with part of their bodies in contact.

Leading a Person Round the Room

This denotes activity in which one person takes hold of the other in some way (usually hand-to-hand contact) and leads him or her in a walk round the room. It is recorded as *one* event if one subject establishes hand-to-hand contact and then the same subject begins leading the other subject. It is recorded as *two* events if one subject establishes hand-to-hand contact and several seconds later the other subject begins to lead him or her. Leading is coded as follows:-

LA - adult leads

LS- PMH subject leads;

LB - subjects walk round together

Specific Actions (Spe)

This denotes any action used by adults to get the PMH subject to do something specific, e.g. the adult takes a young person's hand and tries to get him to bounce the ball on the floor.

Hand Contact to Assist Body Games (Act)

The adult has hand-to-hand contact but is rocking, pulling, pushing the PMH subject (large body movements). This event is coded as follows:-

- ACTA the adult initiates, no observable reaction from the PMH.
- ACTS the PMH subject initiates
- ACTAB the adult initiates and the PMH subject participates in the activities but does not respond in other ways.
- ACTSM the PMH subject initiates and participates in the activities but does not respond in other ways.

Person-to-Person

Attention is focussed mainly on the other person and their non-object actions.

4a. Non-Verbal Reacts

The PMH subject reacts through a non-verbal¹ channel to something the adult is doing, excluding (2b) and (2c), but does not reciprocate further. The event ends at the completion of the PMH subject's reaction.

4b. Mutual Involvement - Action and Movement Games (Adult Init)

The PMH subject reacts to and joins in with play or actions based on specific movement activities such as rocking, bouncing, swinging, tickling, walking round the room together, hand clapping, patting hand/body, stroking. The event lasts until one of the subjects terminates the action.

4c. Interactive Involvement - Adult Init.

There is interpersonal contact, initiated by the adult, in which there are two or more consecutive reciprocal exchanges between the adult and the PMH subject, or the adult and PMH subject react to each other through their spontaneous movements, e.g. 'dance' together.

4n. Non-Verbal Initiates

The PMH subject initiates interpersonal contact through a non-verbal channel in the absence of prompting from the adult, but does not follow this up. If the adult does not respond this is categorised as 'missed cue' (see additional items in next section).

¹This event refers to a single nonverbal feature, e.g. a smile, or co-occurring events in a single, isolated phrase, e.g. a vocalisation and a brief look.

4o. Mutual Involvement - Action and Movement Games (PMH Init)

The PMH subject initiates and joins in with play or actions based on specific movement activities such as rocking, bouncing, swinging, tickling, walking round the room together, hand clapping, patting hand/body, stroking. The event lasts until one of the subjects terminates the action.

4p. Interactive Involvement - (PMH Init)

There is interpersonal contact, initiated by the PMH subject, in which there are two or more consecutive reciprocal exchanges between the PMH subject and the adult, or the PMH subject and adult subject react to each other through their spontaneous movements. This may occur during other categories and takes precedence for its duration.

Additional Items

Missed Toy Offer

The adult ignores a toy/object offered by the PMH subject. This lasts for the duration of the action the PMH subject uses to offer the toy/object.
Code as MTO

Missed Cue

The PMH subject gives a nonverbal cue which is ignored by the adult. This lasts for the duration of the behaviours the PMH subject uses in his/her initiation attempt.
Code as MC

Appendix 3

Study 2 - Reduced Categories: Assignment of Original Codes

The codes assigned to observations in the Shared Involvement Coding Schedule were condensed into five levels of involvement for statistical analysis. The table below shows the allocation of the codes to the five levels.

Codes labelled (1) are from the 'Solitary Activity' category; (2) are 'Focus on Toys'; (3) and (Act; L) are 'Physical Contact'; and (4) are from the 'Person-to-Person' category. The code abbreviations are those listed in the Shared Involvement schedule.

Level of Involvement	Original Codes
Alone	1i, 1ii, 1iii, 1iv
Acknowledge	1v, 2a, 2b, 4a
Passive Involvement	3a, 3b, 3c, 3d, 3e, 3f, LA, Spe, ActA
Active Involvement	2n, 4n, 3g, 3h, 3i, 3j, 3k, 3n, 3o, 3p, 3q, 3r, 3s, 3t, 3u, 3v, 3w, LS, LB, ActAB, ActS, ActSM
Reciprocal Engagements	2c, 2o, 4b, 4c, 4o, 4p